Arizona

Long Term Care Ombudsman Manual

Updated 2/2008

OUTLINE

INTRODUCTION
- Mission of the Ombudsman Program

THE OLDER AMERICANS ACT AND THE DIVISION OF AGING AND ADULT SERVICES
- The Federal Level – The Administration on Aging
- The State Level – State Units on Aging
- The Local Level – Area Agencies on Aging

THE DEVELOPMENT OF THE OMBUDSMAN PROGRAM UNDER THE OAA
- The Long Term Care Ombudsman Program in Arizona

SERVICES OFFERED BY THE OMBUDSMAN PROGRAM
- Investigative Services
- Public Information and Education
- Systemic Advocacy

DUTIES OF THE OMBUDSMAN

ROLES OF THE OMBUDSMAN
- Advocate
- Mediator
- Educator
- Broker
- More About Advocacy
  - Why Do Older Adults Need Advocacy?
  - Forms of Advocacy
  - What an Advocate Should Know
  - The Do's and Don'ts of Advocacy

ACCESS ISSUES
- The Omnibus Budget Reconciliation Act (OBRA) of 1987 (aka The Nursing .Home Reform Act)…
- Arizona Ombudsman Access Policy

LEGAL COUNSEL

CASE STUDIES FOR DISCUSSION

CODE OF ETHICS FOR OMBUDSMAN

SELECTED ETHICAL ISSUES
- Confidentiality
  - Federal and Arizona Policy on Confidentiality and Disclosure
  - What Communications Must Be Guarded?
- Conflict of Interest…
  - Owners and Workers in Long Term Care Services
  - Values

OUTLINE

INTRODUCTION
- The Aging Process
- Attitudes Toward Aging

WHAT IS YOUR AGING IQ?

DEMOGRAPHICS OF AGING IN ARIZONA

PHYSIOLOGICAL ASPECTS OF AGING
- Physiological Changes
- Health Issues
  - Caveat

SELECTED SOCIAL AND ECONOMIC ASPECTS OF AGING

MENTAL ASPECTS OF AGING
- Thinking Abilities
- Emotional Health
  - Changes and Losses
  - Some Reactions/Issues You May See in Older Persons
  - Reminiscence

DEATH AND DYING

POPULATIONS IN NURSING FACILITIES

POPULATIONS IN BOARD AND CARE HOMES

ADMISSION INTO LONG TERM CARE FACILITIES
- Adjustment to Institutionalization

SELECTED ILLNESSES AND CONDITIONS OF THE ELDERLY IN LONG TERM CARE FACILITIES
- Malnutrition
- Hiatus Hernia
- Constipation
- Dehydration
- Osteoporosis
- Parkinson's Disease

MYTHS AND REALITIES OF LONG TERM CARE
- Basis for Rethinking Stereotypes About Long Term Care
- Loss of Mobility
- Pressure Ulcers
- Urinary Incontinence
- Depression
- Safety Concerns
- Summary

OUTLINE

INTRODUCTION
- Long Term Care Settings

HISTORCIAL OVERVIEW

NURSING HOMES
- Types of Nursing Homes
  - Licensed Nursing Homes
  - Licensed and Certified Nursing Homes
- Ownership and management of Nursing Homes
  - Privately-Owned Facilities
    - Proprietary Ownership
    - Non-profit Ownership
    - Chains
  - Publicly-Owned Facilities
  - Information on Ownership
- Industry Associations
- Nursing Home Reimbursement
  - Medicaid
  - Medicare
  - Veterans Administration Benefit
  - Private Long Term Care Insurance
- Selected Departments and Staff of Nursing Homes
  - Administration
  - Medical Staff
  - Nursing Services
- Nursing Home Services and Special Programming
- Regulation of Nursing Homes
  - Federal Level
  - State Level
  - Local Level
  - Federal Regulations and OBRA '87
  - Selected Requirements for Nursing Facilities
  - Other Services
  - Prohibited Practices
  - State Licensure of Nursing Homes
  - (Federal) Certification of Nursing Homes
  - Enforcement in Nursing Homes
  - Other Agencies Involved in Regulating Nursing Homes

ASSISTED LIVING CENTERS
- What is Assisted Living?
- Types of Assisted Living Centers in Arizona
- Ownership and Management of Assisted Living Centers
- Structure, Staff and Training in Assisted Living Centers
- Services and Programming of Assisted Living Centers
- Assisted Living Center Reimbursement
- Regulation of Assisted Living Centers

OUTLINE

APPENDIX D: RESOURCES

Books and Reports
Videos and Game
NCCNHR Publications

Module V: Communicating Effectively with Older Adults

OUTLINE

INTRODUCTION

SETTING THE STAGE FOR EFFECTIVE COMMUNICATION: CREATE A POSITIVE ATMOSPHERE

GUIDELINES FOR EFFECTIVE LISTENING

IMPROVE YOUR VERBAL COMMUNICATION

COMMON BARRIERS TO COMMUNICATION

THREE MESSAGES THAT DESTROY COMMUNICATION (OPTIONAL)

OVERALL GUIDELINES FOR EFFECTIVE COMMUNICATION

GENERAL VERBAL COMMUNICATION PRACTICE EXERCISES

ASSERTIVE VERBAL AND NON-VERBAL COMMUNICATION

SPECIAL ISSUES IN COMMUNICATING WITH THE HEARING AND VISUALLY IMPAIRED ELDERLY

SPECIAL GUIDELINES FOR COMMUNICATING WITH THE ELDERLY WHO HAVE APHASIA

SPECIAL GUIDELINES FOR COMMUNICATING WITH THE ELDERLY WHO HAVE ALZHEIMER'S DISEASE OR OTHER DEMENTIAS

SPECIAL GUIDELINES FOR COMMUNICATING WITH THE ELDERLY WHO ARE UNRESPONSIVE OR WITHDRAWN

SPECIAL GUIDELINES FOR COMMUNICATING WIH CARE PROVIDERS

Module VI: Problem-Solving
Part 1: Complaints, Intakes and Investigation

OUTLINE

INTRODUCTION

OMBUDSMAN APPROACH TO PROBLEM SOLVING
- Uniqueness of the Ombudsman Approach
- Common Problems
- Barrier to Self-Advocacy
- Role of the Ombudsman/Advocate

POLICY CONSIDERATION
- Documentation
- Confidentiality
- Encouraging Self-Advocacy

DILEMAS IN RECEIVING COMPLAINTS

USING THE THREE STATES OF PROBLEM SOLVING

STAGE I: INTAKE, INVESTIGATION AND VERIFICATION
- Intake: Recognizing and Receiving Complaints
- Investigation: Gathering Information
  - Interviewing
  - Observation
  - Using Official Documents
- Verifying and Defining the Problem

SUMMARY

APPENDIX: THE PROBLEM-SOLIVING PROCESS: GUIDELINES FOR PRACTICE

Module VII: Problem-Solving
Part 2: Analysis, Planning, Resolution, Follow Up and Resources

OUTLINE

INTRODUCTION

STAGE II OF THE PROBLEM-SOLVING PROCESS
- Analyzing the Situation
  - Why did the problem occur?
  - What justification or explanation does the nursing home offer for the problem?
  - Who or what is at fault?
- Planning
  - Identifying possible solutions
  - Identifying obstacles

STAGE III OF THE PROBLEM-SOLVING PROBLEM
- Basic Guidelines for Resolution and Follow-Up
- Establishing Trust
- Choosing an Approach
  - Overview
  - Complaint Resolution Strategies
- Acting to Resolve the Complaint
  - Suggestions for Dealing with Authority Figures
  - Factors to Remember in Resolution
- Evaluating the Outcome: Follow Up
- Community Resources and Support Systems
- What an Advocate Should Know
- Working to change the System: The Larger Role of the Ombudsman/Advocate
  - Achieving Long Range Goals
  - Advocacy for Systemic Change

APPENDIX

MODULE I

INTRODUCTION TO THE OMBUDSMAN PROGRAM

Module I: Introduction to the Ombudsman Program

OUTLINE

Introduction

The concept of an *ombudsman* originated in 1809 when the Swedish government changed from a monarchy to a democratic government. The ombudsman was responsible for mediating between the government and the average citizen. He explained policy, shared information, and acted on behalf of the citizens as well as the government. He was to act objectively and impartially. Like the ombudsman of today, he did not have the ability to make administrative decisions, but he had the responsibility and the opportunity to use his knowledge to affect decisions.

Ombudsmen can be found in a number of settings, including businesses and universities. The long-term care ombudsman (referred to only as an "ombudsman" from here on) helps the public - usually long-term care residents - who question the services received in Long Term Care facilities. The ombudsman must be: 1) politically and administratively independent of the facility or agency involved, 2) accessible to all parties concerned, and 3) knowledgeable about long-term care and concerns of the elderly.

The ombudsman's primary role is to help residents to help themselves. Whenever possible, he/she should assist the resident to develop specific strategies to address problems. These strategies may include mediating or negotiating with the facility staff, working with a resident council, getting a group of residents with similar concerns together to work on a problem, or filing a complaint on behalf of the resident.

There may be times when the ombudsman will speak on behalf of the resident or family. This usually occurs when resources within the care setting or community are unknown, when family or legal problems arise, when there is fear of causing tension or reprisal in resident-staff relationships, or when the resident is unable to communicate his/her wishes.

Mission of the Ombudsman Program

The Ombudsman Program exists to protect the human and civil rights of long-term care residents and to promote their autonomy through individual and collective advocacy efforts to enhance their quality of life in long-term care settings. This mission statement requires diligence and commitment to improve the quality of life experiences by Arizona's institutionalized elderly residents.

The Older Americans Act and the Organization of Aging Services

In the 1960's, the needs of the elderly became a growing issue. In 1965, the Older Americans Act (OAA) was passed and signed into law. It has since been revised a number of times. Under the OAA, aging services have a specified organizational structure at the federal, state and local levels. We will discuss the key components at each of these levels.

The Federal Level - The Administration on Aging (AoA)

The central aging network organization at the federal level is the Administration on Aging. AoA administers provisions of the Older Americans Act, except Title V (Community Service Employment for Older Americans). It advocates at the federal level on behalf of older citizens throughout the nation. AoA operates out of the Department of Health and Human Services (DHHS), with a central office in Washington, D.C. and ten regional offices across the nation.

The State Level - State Units on Aging (SUAs)

The basis of the aging network at the state level is the State Unit on Aging, which serves as the focal point for all matters related to the needs of older persons within its area. Each state unit must prepare a state plan that addresses the needs and concerns of its elderly citizens.

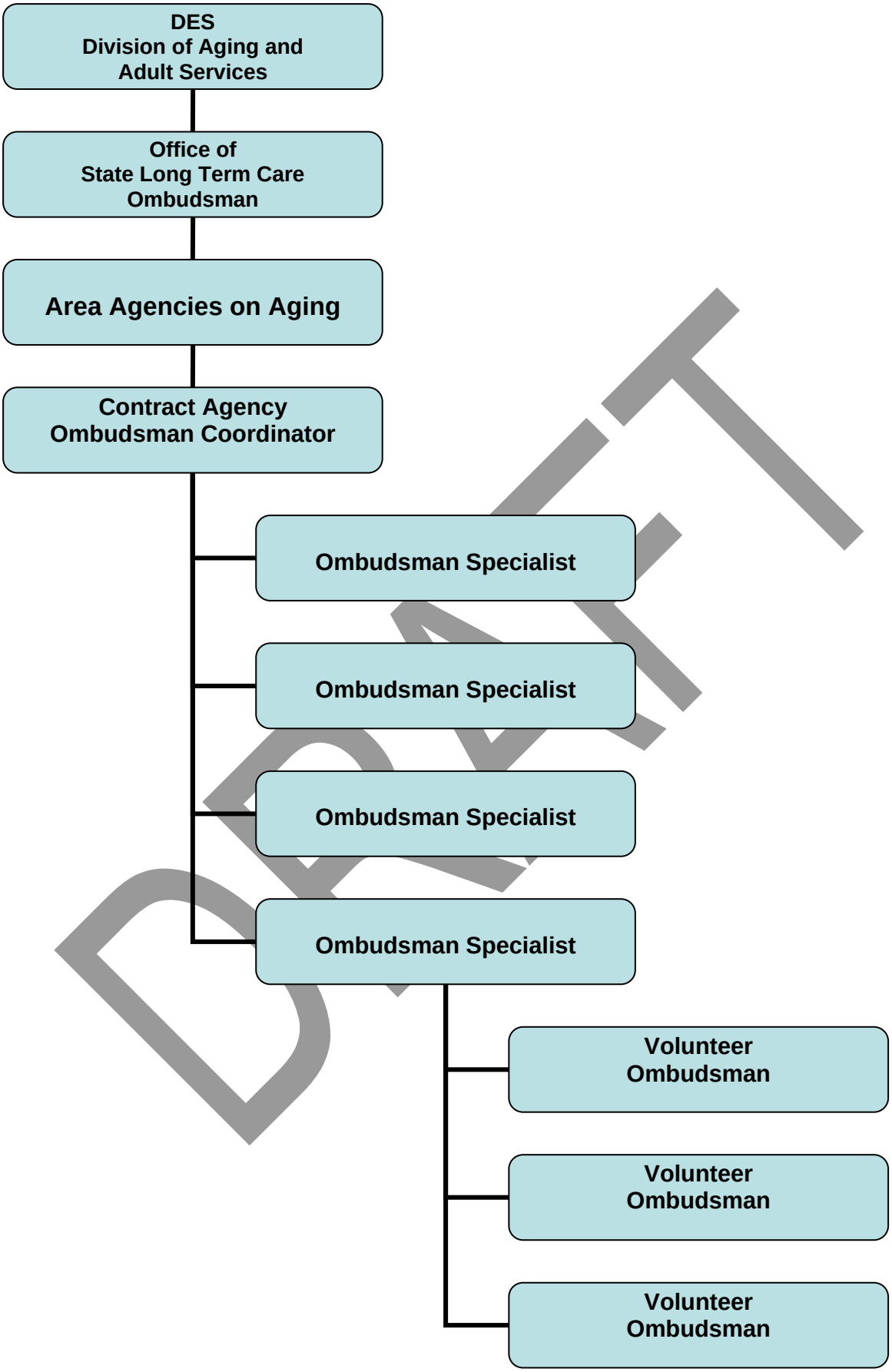
In Arizona, the State Unit on Aging is the Division of Aging and Adult Services in the Department of Economic Security.

The Local Level - Area Agencies on Aging (AAAs)

Most states are divided into several planning and service areas (PSAs). Each PSA is served by an Area Agency on Aging (AAA). The AAA is designated by the state unit on aging to develop and administer an area plan for services to the elderly in its PSA. On the basis of this area plan, AAAs receives sub-grants or contracts from the SUA's allotment under Title III of the Older Americans Act. These are the primary components of the aging network.

The Development of the Ombudsman Program under the OAA

The Ombudsman Program was first incorporated into federal law with the 1972 amendments to the OAA. This amendment required all states to have a nursing home ombudsman program and specifically defined ombudsman functions and responsibilities. A statewide reporting system also was required. In the 1981 amendments to the OAA, board and care homes were added to the program's responsibility. The program name was changed, therefore, to the Long Term Care Ombudsman Program. The 1987 amendments to the OAA resulted in significant improvements in the program's ability to advocate on behalf of long-term care residents and formed the basis of today's Ombudsman Program.


DES
Division of Aging and
Adult Services
Office of
State Long Term Care
Ombudsman
Area Agencies on Aging
Contract Agency
Ombudsman Coordinator
Ombudsman Specialist
Ombudsman Specialist
Ombudsman Specialist
Ombudsman Specialist
Volunteer
Ombudsman
Volunteer
Ombudsman
Volunteer
Ombudsman

The Long Term Care Ombudsman Program in Arizona

In Arizona, the program was authorized by the Arizona Long Term Care Ombudsman Law of 1989 (Arizona Revised Statute 46-452.02 Long Term Care Ombudsman). The Office of the State Long Term Care Ombudsman (OSLTCO) was established within the Division of Aging and Adult Services, and is headed by the State Long Term Care Ombudsman. How the program is structured varies significantly from state to state. In all states, the State Ombudsman has the authority to designate local agencies to administer the program at the sub-state level. The State Unit on Aging may contract with the Area Agency on Aging to provide ombudsman services at the local level directly, or the AAA may contract with another agency to provide the service. In Arizona, most designated agencies are area agencies on aging, but one local ombudsman program is located at a not-for-profit service agency. The ombudsman service areas in Arizona are shown in your handout.

At the local level in Arizona, there are three personnel roles in the ombudsman program: ombudsman coordinator, ombudsman specialist and volunteer ombudsman.

The Ombudsman Coordinator:

- provides administrative oversight, coordination and direct intervention of the ombudsman program
- assures completion of monthly and ad hoc reports and proper documentation of activities
- acts as the liaison to the state ombudsman
- provides supervision to ombudsman specialists
- assigns facilities as needed
- maintains cooperative relationships with Department of Health Services licensure
- staffs situations and recommends interventions and strategies that are supportive of clients' rights
- counsels families, facilities and residents in problem resolution
- utilizes community resources to effect problem resolution
- visits facilities to establish rapport, to investigate and assist in resolving complaints

The Ombudsman Specialist

- recruits, trains, places and oversees volunteer ombudsmen and provides supervision of volunteers working in the ombudsman program
- receives all complaints and ensure follow-up by coordination with long term care facilities and/or refers complaints to the appropriate agency
- provides resident advocacy for individuals living in long term care facilities
- assists residents to maintain their dignity, autonomy, rights and choice in every day life and care
- provides technical support for the development of resident and family councils to protect the well being and rights of residents
- assists residents and their families to understand resident rights and facility policies and applicable regulations
- engages in advocacy activities, public information and referrals to licensing and other enforcement agencies
- maintains records and reports on complaints and follow-up actions
- provides reports and other statistical data on ombudsman program activities
- assures confidentiality of resident issues and
- follows proper disclosure information on all complaints

The Volunteer Ombudsman

- visits once a week for 2 hours to one or more assigned facilities
- can serve as a liaison between residents, their families, and facility personnel
- investigates and resolves complaints within the assigned facility
- reports complaints to his/her coordinator
- refers unresolved complaints to the local ombudsman coordinator

Services Offered by the Ombudsman Program

Complaint Investigation

The program receives, investigates and resolves complaints made by or on behalf of persons who are residents of long-term care facilities relating to action, inaction, or decisions of providers, or their representatives, of long-term care services, of public agencies, or of social service agencies, that may adversely affect the health, safety, welfare, or rights of such residents. A complaint is defined as a problem, concern, or issue reported to, or observed by, an ombudsman on which the ombudsman takes action on behalf of the resident(s) to affect the outcome of the situation or solve the problem.

Public Information and Education

The Ombudsman Program provides information and public education to assist individual residents, or individuals requesting the information on behalf of a resident, concerning the long-term care system, the rights and benefits of residents of long-term care facilities, and services available to residents including the activities of the ombudsman program. Public education activities include public speaking engagements, sponsoring or conducting workshops, promoting the development of community organizations to participate in the ombudsman program, developing and distributing written materials, and promoting media coverage of long-term care issues.

Issue Advocacy Within the Long Term Care System

In accordance with federal law, the Long Term Care Ombudsman Program monitors the development and implementation of federal, state, and local laws, regulations and policies that relate to long-term care facilities. Often, ombudsmen are involved in initiating changes in legislation or policy.

Duties of the Ombudsman

Under federal and state law, the Long Term Care Ombudsman has many duties, which include:

1. Provide services to protect the health, safety, welfare and rights of residents;
2. Ensure that residents in the service area of the Ombudsman Program have regular, timely access to representatives of the program and timely responses to complaints and requests for assistance;
3. Identify, investigate, and resolve (by agreement, mediation or conciliation) complaints made by or on behalf of residents that relate to action, inaction, or decisions, that may adversely affect the health, safety, welfare, or rights of the residents;
4. Render advice to residents of facilities;
5. Represent the interest of residents before government agencies and seek administrative, legal, and other remedies to protect the health, safety, welfare, and rights of residents, including:
    - referring cases involving abuse, neglect, exploitation or health and safety to Adult Protective Services or the appropriate licensing agency, and
    - making appropriate referrals to legal or other community services;
6. With regard to laws, regulations, policies and actions, ombudsmen also have the duty to:
    - review, and if necessary, comment on any existing and proposed laws, regulations, and other government policies and actions, that pertain to the rights and well-being of residents; and
    - facilitate the ability of the public to comment on the laws, regulations, policies, and actions;
7. Support the development of resident and family councils; and
8. Carry out other activities that the ombudsman determines to be appropriate.
9. Official duties of the State Long Term Care Ombudsman do not include activities performed by a licensed health care provider as defined in state law.

To accomplish these duties, the ombudsman has the authority to enter long-term care facilities to communicate with residents.

Roles of the Ombudsman

In carrying out these duties, the ombudsman plays many roles, including advocate, educator, mediator and broker.

Advocate

This is often used as a generic term for what ombudsmen do, but in looking at roles, it has a very different meaning and function from other roles. As an advocate, the ombudsmen works on behalf of a resident in resolving complaints that have been substantiated and need specific strategies developed to alleviate the problem that was identified. Advocacy may take the form of negotiating with an administrator or other staff; filing a complaint on behalf of the resident; working with a resident council; or getting a group of residents who have similar concerns together and working to resolve the problem as a group.

Educator

An ombudsman works to educate residents, families, friends or potential consumers about their rights and responsibilities in a facility. Ombudsmen need to have a working knowledge of current federal and state residents' rights in order to answer questions. Ombudsmen should also provide information to concerned individuals who wish to advocate for themselves but don't know how to. Handbooks (e.g., "How to Select a Nursing Home" or "Resident Rights Handbook") can be used to provide supplementary information.

Mediator

The Ombudsman may serve as a mediator between resident and staff, resident and community or local government agency, resident and other residents, or resident and family. In this role the ombudsman may be a spokesperson for the resident, communicating the concerns to the appropriate staff, agency or family member in an effort to see the grievance or problem resolved. At times the response may be immediate and satisfactory.

The agency or individual may be unaware of the problem until it surfaces through the

efforts of the ombudsman, and the resolution may be relatively simple. A large percent of problems results from misunderstandings or breakdowns in communication. Clarification by the ombudsman may be all that is necessary.

A mediator helps the parties find an acceptable solution by following a complaint or grievance through to resolution. In this role, ombudsmen do not impose their own solution, but help those involved to find and agree upon their own acceptable solution.

Broker

A broker's role is essentially that of a referral agent. When an ombudsman investigates a problem and finds that another agency could better resolve it or is essential to the process, a referral should be made. Referrals will often be made to many of the same resources used in performing information and referral duties. After making the referral, the ombudsman should remain in contact with the agency to which he/she made the referral, checking on progress and reporting back to the complainant. The ombudsman may not have the power to insure prompt service, but his conscientious follow-up may help "oil the wheels."

More About Advocacy

Although the original concept of ombudsman meant an impartial mediator, long-term care ombudsmen usually are not impartial in their complaint resolution work. Ombudsmen must take the resident's perspective in trying to resolve a problem. If residents can represent themselves, they should be encouraged to do so, but ombudsmen may assume a mediator role to ensure that the residents' views are heard and that everyone participates in determining the resolution. You can imagine these tools as hanging on a construction worker's tool belt, and the construction workers hat says "advocate." Just as a construction worker never removes his hat when hammering or sawing, the ombudsman never removes the "advocate" hat in serving as a broker or educator.

The brokering or education is simply a tool to reach the overall goal of advocacy on behalf of the resident.

There are some things that an ombudsman is not. An ombudsman is not a:

- **FACILITY STAFF PERSON -** the facility would be happy if you would take the role of a staff member and push wheelchairs or deliver meals. The ombudsman should not accept this role because it will use lots of your time and confuses your role (and your separateness from the facility) in the eyes of the resident.

- **CAREGIVER** – an ombudsman should not give care to the resident. When a resident wants medication, a position change, or other care services, a facility staff person should do the work. This prevents us from unknowingly causing an injury, insulates us from legal liability, and most importantly tests or assures that a service system can meet the residents needs for all of the hours we are not there to fulfill the resident's request.

- **SMUGGLER** - the ombudsman should never bring cigarettes, liquor, medications or other supplies to the resident.

- **SAVIOR** - the ombudsman should work hard to meet the resident's request. However, we should never *promise* things that we know are impossible to accomplish or that are not clearly within our control.

- **LAWYER** - if a resident needs legal advice, we should connect them with the appropriate resources.

- **INSPECTOR/REGULATOR** - we are representatives of the residents. We do not go into a facility with a list of regulations and see if any are violated. Rather, we listen to the residents and act upon their concerns.

Ombudsmen have a unique role that requires objectivity in investigating problems or complaints and advocacy skills in resolving those problems. Objectivity is required to determine the validity of complaints. Sufficient information must be gathered to have an accurate understanding of the problem and to plan a resolution strategy. In resolving problems, however, ombudsmen are advocates working on behalf of the resident.

The root of the word *advocacy* means *speaking for, i.e., using your voice on behalf of some person.* Thus, advocacy has been described as action on behalf of an aggrieved person through direct intervention, or on behalf of an entire class of aggrieved persons through attempted change in policy.[1]

Case advocacy assumes a partisan stance on behalf of a person or a group of people who cannot negotiate their demands alone, find redress for grievances, or cut through bureaucratic red tape.[2] In summary, then, advocacy can be described as involving:

- acting on behalf of another
- pleading another's cause
- assisting another to represent himself/herself
- a willingness to study, to learn, to gather information necessary to support a cause.

Advocacy in the Ombudsman Program exists primarily to represent the expressed concerns of long-term care facility residents who are relatively without influence or representation within a facility. By extension, the ombudsman will represent the concerns of the relatives and/or friends of long-term care facility residents, taking care to determine the degree to which such concerns reflect the concern of the residents. Ombudsmen often find that they must plead on behalf of an older adult for services to which he or she is entitled but has been unable to obtain alone. In acting as an advocate, an ombudsman may:

- Press an older individual's case with another agency
- Press an agency for changes in its policies and procedures on behalf of older persons using the agency's services
- Press for changes in public policy on behalf of all people in long term
- care facilities

[1] Richan, W.C. "The Administrator as Advocate" in Perlmutter, F.D. and Slavin, S. Leadership in Social Administration, Philadelphia : Temple University Press, 1980

[2] Lowy, L. Social Work with the Aging, NY: Longmans, 1985.

Why Do Older Adults Need Advocacy?

As we get older, we tend to develop problems that gradually force us to depend on some degree of assistance from others. While family and friends provide a great deal of support, many older adults also need help from home and community-based programs or residential facilities. These services can be complicated, with a wide range of laws, regulations, rules and procedures, as well as informal practices and numerous written forms. It is difficult or impossible for most people, especially those who are ill, to understand all these complexities. In addition, it may be necessary to prompt and prod service providers to fulfill service obligations.

Again, most people do not know the "who's" and "how's" of spurring a bureaucracy into action. An advocate helps to meet these needs.

As an advocate for long-term care residents, you are likely to be dealing primarily with the resident, the long-term care staff and the governmental enforcement agency. You may find yourself attempting to convince the facility to change a policy or practice that is causing a resident a problem. At the same time, you may be attempting to spur the enforcement agency to take action within the facility to cause the desired change.

Forms of Advocacy:

Ombudsmen work in a variety of ways to improve care for assisted living and nursing facility residents. Often the avenues for advocacy are intertwined, building upon each other. A state ombudsman may be working on system-wide changes while a local ombudsman is working on a resident's problems; yet their efforts are interconnected and complementary. Effecting lasting change takes the combined efforts of the entire ombudsman network. Among the forms of advocacy are:

- ***Working to Resolve Individual Problems*** provides immediate assistance to residents. Ombudsmen hear concerns from many sources: from residents, families, friends, facility staff and others. Most of these concerns are about nursing care, food, finances, sanitation, and activities. Ombudsmen are trained in complaint handling techniques and authorized by the Older Americans Act to investigate and resolve problems.

- ***Making Overall Changes* in the Facility** may be necessary if the facility's care practices or policies are at the root of the problems residents' face. Advocates often work hard to open lines of communication between facility administration and residents and their families. A change in attitude may be necessary before a facility can be a comfortable place for residents.
- ***Extending Community Resources to Residents*** is essential because no one institution can meet all the needs of all its residents. Residents have social, legal, financial, recreational, personal, intellectual, and spiritual needs. They may also need to locate services to assist in obtaining clothing and personal items. The ombudsman must work with the facility to identify appropriate community resources.
- ***Necessary System-wide Changes*** may be essential to achieve an effective resolution to a problem. This might mean changes in regulations or laws or improvements in an enforcement system. System-wide changes may also occur as a result of educational efforts. Ombudsmen play an essential role in effecting legislative and regulatory change. Their work serves to inform decision-makers about the concerns of the residents and the problems that affect the resident's quality of life and care. The 1987 Nursing Home Reform Amendments were based in large part on the work of ombudsmen and other advocates.
- ***Empowering Residents and Citizens*** is an integral part of the daily work of an ombudsman. The ultimate goal is to have residents and citizens of the community advocate for improved quality of life and quality of care in their nursing facilities. The ombudsman enables residents and the community to engage in self-advocacy by educating residents, families, friends or potential consumers about their rights in a facility, by providing information, by encouraging and supporting such efforts, and by being a positive role model. Thus, ombudsmen need to have a working knowledge of resident's rights under state and federal law and current state and federal regulations governing long-term care facilities.

A good advocacy program responds to the interrelationship of all these forms of advocacy. While one program, or advocate, may not be able to emphasize every aspect of this wide range of activities, the program should see itself as part of a network of activities in which all forms of advocacy support each other.

Just as the program operates through teamwork with other programs, the members of an advocacy program need to work well as a team, complementing one another's talents and recognizing the necessity of all contributions to the total effort. Ombudsmen can assist each other in the development of skills, strategies, and an "information bank."

What an Advocate Should Know[3]

A good advocate must be knowledgeable about nursing home conditions and issues. There is no substitute for current, factual information to support your advocacy efforts. A good advocate must know about the nursing homes in the immediate community.

- What kind of facilities are they? What level of care do they provide? Are they private pay and therefore do not participate in the Medicaid or Medicare programs?
- Who lives there? The very old and very ill? Young people? Mentally ill? Disabled? How many beds does each facility have?
- What kinds of special programs does the facility offer? Rehabilitation? Community interaction? Physical therapy? Mental health services? Residents' council? Family council? Does the facility provide the services that it advertises in brochures, telephone books, and the newspaper?
- Does the facility have a dementia special care unit? If so, what makes it "special"?
- What is the general atmosphere of the facility? Warm/cold. Friendly/sterile?
- Which facilities offer special model programs that could be duplicated by others?
- Which facilities have warm, receptive staff that encourages the public to visit?
- What kind of training is provided for the nursing assistants? How are the working

[3] Adapted from: The National Citizens' Coalition for Nursing Home Reform

conditions for staff?

- How does the facility measure up in meeting standards? What do inspection reports say about conditions? Go to the DHS website: www.azdhs.gov

The DO's of Advocacy:

1. Respect the confidentiality of all complaints made to you.
2. Be a good listener.
3. Assure the residents that you are there to listen to their problems.
4. Speak clearly and slowly so the resident can understand you.
5. Try to talk to the resident in a quiet, private area.
6. Explain things in a few words, rather than in long paragraphs.
7. Be objective, yet understanding.
8. Try to provide an accurate picture to the residents of what they can expect.
9. Attempt to make the residents feel you care and are there to help them.
10. Work with residents, the staff, and the administration in solving problems.
11. Keep accurate records of problems as requested for evaluation of the program.
12. Remember that it may take some questions and perseverance to get to the real or underlying problem.
13. Make an attempt to understand the total situation or problem by seeking out as many sources of information as possible.
14. Remember that some residents may distort or exaggerate; therefore, an accurate and reliable assessment of the problem is necessary.
15. Remember that the resident may tire easily, have a short attention span, digress during conversations, or simply become confused. Be patient.

The DON'Ts of Advocacy:

1. Do not provide physical or nursing care, which is the responsibility of the trained nursing staff in the facility. This rule is for the patients' protection, as well as the advocate's.

2. Do not bring unauthorized articles into the home, such as food, drugs, prescriptions, tobacco, alcoholic beverages or matches.

3. Never treat the residents as children. They have had a lifetime of experience.

4. Do not diagnose or prescribe for a resident.

5. Do not make promises which may be impossible to keep (e.g., "I'll fix everything.")

6. Do not advise residents on business or legal matters.

7. Do not be critical of the residents or the long-term care facility.

8. Do not engage in arguments, but rather stick to the question or problem at hand.

9. You are not an inspector of the facility. You are there to listen to individual complaints and try to resolve them. However, if in the course of visiting with residents, a violation is noticed, it should be reported to the administration for correction or, in the case of a volunteer to the ombudsman coordinator.

Access Issues

The Omnibus Budget Reconciliation Act of 1987 (OBRA '87) and Access

OBRA '87 grants representatives of the Ombudsman Program immediate and unlimited access to any skilled nursing home resident and access to records with the permission of the resident and consistent with state law. Records access requires the written permission of the resident, or a legal representative. A legal representative is a guardian, a person with Power of Attorney or someone else designated to act on the resident's behalf. A responsible party is not a legal representative unless they also hold Power of Attorney or have been named as guardian.

Arizona Ombudsman Access Policy

Certified Ombudsmen shall utilize the following procedure when entering a long-term care facility to identify, investigate and resolve complaints regarding long-term care residents.

a. **Facility Access**

(1) Certified ombudsmen (paid or volunteer) have the same right of access to long-term care facilities and residents as the State Ombudsman.

(2) Ombudsmen may sign the guest register or notify designated staff of their presence when they are responding to a complaint.

(3) Reasonable hours of access are defined to be between 8:00 a.m. and 8:00 p.m., Monday through Sunday. The ombudsman will discuss or make arrangements with facility staff to discuss complaints when his/her assistance is needed to resolve an issue.

(4) Entry by ombudsmen between 8:00 p.m. and 8:00 a.m. shall be made after a request is made by the ombudsman coordinator and after authorization is received from the State Ombudsman or designated representative.

(5) If an ombudsman is denied access to a long-term care facility, the ombudsman will relate the incident to the ombudsman coordinator. The coordinator will discuss the issue with the administrator, making reference to the appropriate federal and state regulations granting certified ombudsman access to such facilities.

(6) If access to a facility continues to be denied, the problem will be referred to the State Ombudsman for resolution.

b. **Resident Access**

(1) The resident has the right to communicate privately or refuse to communicate with a certified ombudsman.

(2) The ombudsman shall knock before entering a resident's room; and shall identify him or herself to the resident.

(3) If denied access to the resident, the certified ombudsman and/or the ombudsman coordinator will discuss with the administration of the facility the applicable federal and state regulation addressing resident rights.

(4) If access to a resident continues to be denied the problem will be referred to the State Ombudsman for resolution.

c. **Records Access**

The ombudsman coordinator and qualified ombudsmen volunteer shall observe the following procedure to review records:

(1) Authority to review medical or personal records must be obtained by the written consent of the resident or his legal representative.

(2) The ombudsman shall use the consent form (entitled "Authorization for Release of Confidential Information") to review client records.

(3) The resident may give consent orally if disability prevents written consent. (Use the "Authorization for Representation and Release of Confidential Information," which requires a witness.) This consent shall be documented in the resident's record.

(4) Cases involving residents who cannot give informed consent and have no legal representative or the legal representative refuses to give consent to review records shall be referred to the appropriate community resource.

Legal Counsel

In accordance with the Older Americans Act, the state will ensure that adequate legal counsel is available to the Office of the State Long Term Care Ombudsman for advice and consultation and that legal representation is provided to any representative of the office against whom suit or other legal action is brought in connection with the performance of such representative's official duties. Ombudsman programs use legal advice and consultation for two purposes:

1. Probably the more frequent use is advice to assist the ombudsman to solve a client's problem. Examples include: clarifying the laws which affect residents of a long-term care facility and exploring alternative problem-solving strategies on behalf of clients, be they individual cases or systems problems.

2. Advice to support an ombudsman investigation. Examples include: clarifying laws on access to facilities and residents' records and understanding how to document a case to support further administrative or legal action on a case.

Case Studies for Discussion

(Information will be provided at a later date)

Code of Ethics for Ombudsmen

Respect for the rights and well being of residents, families and providers requires that Ombudsmen behave ethically. Regardless of an ombudsman's level(s) of advocacy effort, or the complexity of the issue/problem which is being addressed, there is a basic set of principles which guide an ombudsman's decisions.

The National Association of State Long Term Care Ombudsman Programs developed the following Code of Ethics for ombudsmen.

1. The ombudsman provides services with respect for human dignity and the individuality of the client unrestricted by considerations of age, social or economic status, personal characteristics or lifestyle choices.

2. The ombudsman respects and promotes the client's right to self-determination.

3. The ombudsman makes every reasonable effort to ascertain and act in accordance with the client's wishes.

4. The ombudsman acts to protect vulnerable individuals from abuse and neglect.

5. The ombudsman safeguards the client's right to privacy by protecting confidential information.

6. The ombudsman remains knowledgeable in areas relevant to the long term care system, especially regulatory and legislative information, and long term care service options.

7. The ombudsman acts in accordance with the standards and practices of the Long Term Care Ombudsman Program, and with respect for the policies of the sponsoring (contract) organization.

8. The ombudsman will provide professional advocacy services unrestricted by his/her personal belief or opinion.

9. The ombudsman participates in efforts to promote a quality long term care system.
10. The ombudsman participates in efforts to maintain and promote the integrity of the

Long Term Care Ombudsman Program.

11. The ombudsman supports a strict conflict of interest standard which prohibits any financial interest in the delivery or provision of nursing home, assisted living centers, or other long term care services which are within their scope of involvement.

12. The ombudsman shall conduct him/herself in a manner which will strengthen the statewide and national ombudsman network.

In carrying out the mandate of the Older Americans Act, ombudsmen serve as part of both statewide and national advocacy networks. The network's structure and function are set forth in federal law, further refined by state law and policies. Ombudsmen are advocates, working on behalf of residents. Ombudsmen conduct themselves in accordance with the Code of Ethics developed by the National Association of State Long Term Care Ombudsman Programs.

Selected Ethical Issues

Now that we have reviewed the Ombudsman Code of Ethics, there are two ethical issues which will be discussed in more detail: confidentiality and conflict of interest.

Confidentiality

If a resident or family member lets you in on a problem, he or she has entrusted you with something that is highly valuable. Except in very rare circumstances, this information must remain in your safekeeping unless you are explicitly given permission to divulge it.

This confidentiality is important, as it respects the individual's dignity and privacy. The resident may fear reprisals, including discharge from the facility and maltreatment from staff and the ombudsman could be sued.

Federal and State Law Regarding Confidentiality and Disclosure:

Federal and state law requires that the OSLTCO, regional ombudsman staff and volunteers shall follow these requirements:

No complaint or other confidential information including the identity of a complainant, resident or records maintained by the ombudsman program shall be disclosed unless:

(1) disclosure is authorized in writing by the resident or his legal representative and specifies to whom the identity may be disclosed, or

(2) disclosure is authorized orally, when written consent is not practicable. Oral consent must be documented in the case record; or

(3) required by a court order.

To summarize, confidential information includes the client name, referral source, address, phone numbers, photographs, records, diagnosis, any tape recordings, and family names, addresses and phone numbers, as well as the entire ombudsman case record.

The ombudsman must never release the name of a resident, family member, or any complainant to any person or agency without the express written consent of that individual or representative. Furthermore, the ombudsman must avoid offering any information that may lead other parties to identify a resident, family member or other complainant.

Except in cases of a court order, ask yourself two questions before using a resident's name:

1. Did he/she or a representative give me permission to divulge his/her name?
2. Does the person to whom I am relating this case need to know the name?

If the answer to either of these questions is "No," keep the case anonymous.

It is difficult to know how to treat the ombudsman's observations of a resident. Suppose that a resident is unable to give her consent to use her name and has no representative. You (as an ombudsman) observe skin breakdown and a foul odor. What do you do? Now suppose that in this case the person has not told you anything confidential. You are aware of the problem because of your observation skills. What do you do?

What Communications Must Be Guarded?

All workers in the program are expected to treat several forms of communication as confidential, including:

1. Conversations with residents, long-term care facility employees, residents' families and others in the scope of ombudsman duties;
2. Investigation discoveries; and
3. Correspondence and records related to residents.

Conversations/Interviews: When an ombudsman conducts a conversation or interview with a resident or staff member about a concern or problem with which a resident has requested help, the ombudsman needs to be aware of several aspects of confidentiality.

- Assure that the interview takes place in a private area so that staff, visitors and other residents do not hear the conversation.
- Any part of an interview or conversation that would reveal the identity of a resident or complainant should not be revealed to staff, residents or another agency without the permission of the resident or complainant. If the information is of a general nature or a condition one could observe in a tour it can be discussed without permission of the resident.
- When an ombudsman documents an interview and the complaint handling process in a case file, those files must be stored in a secured area in the ombudsman's office.

Letters and Memos to other workers in your agency or the Ombudsman Program, whether in the local or state office, may contain identifying information only with the consent (written, if at all possible) of the resident.

Correspondence to and from the ombudsman that may contain identifying information must be guarded. Such incoming mail should be marked *Confidential* and should be opened only by the ombudsman. Outgoing mail should be handled by the ombudsman, and the clerical staff should be trained to maintain confidentiality.

Any paperwork (notes, logs, copies of medical records, etc.) that may contain information that could identify a resident must be kept in a locked cabinet.

Examples of confidentiality-related situations include:

a. If you want advice and need to send information to the State Ombudsman, but do not have permission to disclose a name, obliterate identifying information.

b. If you are referring a complaint to the State Ombudsman but do not have permission, you must obliterate the names of those who have not given you their consent to use their name. This lays a heavy obligation on you to describe the situation accurately so that another investigator may discover

the problem without causing the complainant to become suspect and subject to reprisal.

c. If you determine that an investigation could cause problems for your agency, you may discuss these problems in general terms with your supervisor even if your supervisor is not a certified ombudsman. However, you must avoid names or other identifying information unless you have specific permission from the resident to reveal such identifiers.

If a resident is hesitant to give an ombudsman permission to disclose information, he/she can do several things.

- Advise the resident that state law forbids retribution and reprisal.
- Discuss any limitations the program may have in guaranteeing no retribution.
- Consider alternative ways of handling the complaint.
    - Consider if you can observe the problem yourself and complain based on your own observation.
    - Consider if the complaint is so widespread that no one resident need be singled out.
- If the resident wishes to remain confidential, advise the resident of any limitations this will place on your ability to handle the complaint.
- Remember that the resident's wishes determine what we do.

The importance of confidentiality to the ombudsman program cannot be over-stressed! The ombudsman's highest responsibility is to safeguard and assure the privacy of privileged resident communications - both for the sake of preserving and promoting resident's rights and for the ombudsman's own self-protection.

Conflict of Interest

Because the ombudsman must be able to pursue the resolution of problems aggressively and without bias, federal law requires the Division of Aging and Adult Services to ensure that there are no conflicts of interest within the ombudsman program. Because there are many situations in which conflicts may arise, it is not possible to list every area of operations that should be examined.

However, some possible conflicts for state or local organizations include:

1) receiving funding from the industry; and

2) having the policy board unduly influenced by the industry perspective.

Possible conflicts for individual ombudsmen include:

1) having financial investments in the long-term care industry;

2) receiving financial gain such as, salary or consultation fees;

3) being a former employee of the industry; and

4) seeking employment in the industry.

These types of conflict of interest are screened for in the application process for ombudsmen.

Let's look in a little more detail at areas that have been known to be problematic with regard to conflict of interest.

Owners and Workers in Long Term Care Services:

While it is clear than an owner or employee of a long-term care facility should not serve as an ombudsman where he or she is employed or has a financial interest, the program should consider that conflicts of interest may arise if an ombudsman works for any agency that is in direct, or even indirect, competition with a long term care facility. Long term care facilities may consider community-based long term care services such as adult day care centers to be competitors

Values:

The ombudsman's primary interest is in the good of the resident ***as the resident sees it***. When ombudsmen hold values that differ from the resident, there is a potential for a conflict of interest. Conflicts may also arise when residents and family members differ in what they request or think is best for the resident.

As a representative of the OSLTCO, the local ombudsman coordinator is responsible for remaining vigilant for conflicts of interest within the local ombudsman program. Coordinators should notify the State Ombudsman when conflicts are suspected and should work with the State Ombudsman to prevent or eliminate such conflicts when they arise.

MODULE II

AGING, THE ELDERLY, LONG-TERM CARE RESIDENTS AND FAMILIES

MODULE II AGING, THE ELDERLY, LONG-TERM CARE RESIDENTS AND FAMILIES	

Learning Objectives:

1. To recognize stereotypes of aging.

2. To understand basic physical, social, and psychological aspects of aging.

3. To understand basic issues and responses related to death and dying.

4. To understand characteristics of populations in nursing facilities.

5 To understand characteristics of populations in board and care homes.

6. To understand the issues involved in, and adjustment to, institutionalization.

7. To be aware of the characteristics of selected illnesses and conditions of the elderly in long-term care facilities.

8. To understand selected myths and realities of long-term care.

OUTLINE

Introduction

To better understand the population of long term care residents who are your primary focus, you need to understand the “big picture” of the senior population. In talking about *aging, older adults,* or *aged persons*, it is helpful to define terms. Who are aged people? At what age does a person become old? When a sixty-four year old goes to bed and wakes up the next morning as a sixty-five year old, has that person changed? Chronological age does not always correspond to a person's feelings. Although a person may be eighty years old, the person may feel like he/she is forty. The age a person feels may vary with the time of day, the day of the week, and activities or stresses which are present in that person's life. A person may be very energetic on a Saturday and very tired and slow moving on Monday morning. Knowing a person's chronological age does not give an accurate picture of that individual's feelings or abilities. Nevertheless, in this country we categorize individuals by chronological age.

Throughout this training program, terms like "aged", "elderly", "older adults" and "older people" are used to indicate persons aged 65 years and over. There is nothing scientific in the selection of age 65 as the beginning of old age. It is arbitrary and is used simply as a matter of custom. Moreover, the definition of "old" varies among ethnic groups and societies. Physically hard work, poverty, malnutrition and illness can "age" people more rapidly

The Aging Process

What is aging? Aging is a continuous process from birth to death which encompasses physical, social, psychological and spiritual changes. Some of the changes are anticipated with joy (like a baby's first teeth or first steps). Other changes are viewed with a less positive response (like the first gray hairs).

Attitudes Toward Aging

Although aging is an ongoing process, societal attitudes differ at various points of the process. Youth is valued while signs of aging are masked with face lifts, wrinkle creams, and hair dyes. The process of physical maturation that is so eagerly anticipated in the first stages of life is viewed very negatively when the youthful attractiveness begins to change. The prevailing attitudes lead to a denial of the signs of aging. Some individuals quit acknowledging birthdays after a certain age. Therefore, the stereotype of aging as a period of deterioration and decline is perpetuated. The positive aspects of aging are ignored. Each stage of life, of aging, has its own pluses and minuses. Sometimes in old age, the balance may tip to more negatives than positives, but this is not due to the *natural aging process*.

In discussing aging and the elderly population, it is important to remember that older adults vary a great deal in their characteristics, problems and needs. A person at age 65 is typically very different from the same person at age 95. Moreover, the aging process varies significantly between individuals. One person may have no chronic illnesses (e.g., arthritis) or vision impairments at age 85, while another might be seriously impaired at that age. Our discussion is not meant to imply that all elderly persons are the same. Rather, it is meant to sensitize us to changes, problems, and needs that people tend to face more often as they get older.

In addition, our discussion may not present a balanced picture of the aged. Due to time constraints, we will tend to focus on problems of the elderly. However, it is important to remember that there are large numbers of healthy, active elderly persons.

DEMOGRAPHICS OF AGING IN AZ

(THIS INFORMATION WILL BE INCLUDED AS A SUPPLEMENT)

Physiological Aspects of Aging

To some degree, normal aging involves a gradual decline in the functioning of the body's systems. We will briefly examine some of these changes:

Bones - The spongy cushion between vertebrae in the spine gradually loses resiliency and flattens, resulting in shorter stature. Older persons also may develop a curvature of the upper spine. Bones tend to decrease in mass. Osteoporosis, a loss of calcium from the bones, can result in fractures. It is most prevalent in elderly white women. The fear of broken bones and inflammation of joints (arthritis) often reduce both mobility and exercise.

Muscles - Some degree of decline in muscle mass, tone, strength, elasticity and endurance reduces physical capabilities and mobility. While exercise helps to maintain strength and tone, it does not prevent all loss. A slowing of muscular reflexes lengthens reaction time.

Skin - Changes include drying of skin (due to loss of natural oils), loss of elasticity (sagging), loss of fat under the outer layer of skin ("thinner skin" that tears and bruises more easily), and reduction of sweat glands (reduced ability to adapt to high temperatures). There is a decrease in the ability to maintain body temperature when exposed to temperatures under 68 F. Healing of damage to the skin becomes slower. Older people may develop "age spots," which are simple changes in the pigmentation of the skin. Although these spots are not related to liver function (as some believe), they should be closely observed for sudden growth or changes in appearance. Such changes should be reported to a physician.

Digestive and Excretory Systems - These systems tend to slow down and become less efficient, which limits the availability of needed nutrients and increases the likelihood of urinary tract infections and dehydration. The supply of saliva, which is necessary to swallow food, decreases, as does the thirst response. Other changes largely depend on exercise, diet and medications. For example, reduced exercise may foster constipation.

Urinary System - The bladder doesn't stretch to hold as much as people age, so urination may be more frequent. A general weakening of the bladder muscles means that the impulse to urinate cannot be delayed as long as in earlier years. When an older adult says, "I have to go to the bathroom," that usually means **now**. Weakened muscles also may cause the bladder not to empty completely, which increases susceptibility to urinary tract infections. The kidneys filter the blood more slowly than in younger years. As a result, medications remain in the blood longer than in younger people, compounding the danger of over-medication and drug interactions.

Respiratory System - Lung capacity and respiratory efficiency tend to decline, reducing the oxygen supply to the body's muscles, brain and other organs. These changes can affect physical and mental capabilities. The elastic recoil of lung tissues decreases, increasing shortness of breath and susceptibility to colds, flu and pneumonia.

Circulatory System - The heart - like other muscles - weakens and has diminished pumping capacity. At the same time, blood vessels tend to become thick and hard, making it more difficult for the heart to pump blood throughout the body effectively. Consequently, capacity of the circulatory system decreases substantially by age 65, and blood pressure tends to rise. Among the many possible effects are feeling cold, impaired physical and mental capabilities, stroke and heart attack. The consequences of these changes may first be observed when an older person stands up quickly and falls or becomes unsteady.

Nervous System - The speed and efficiency of the nervous system tends to decline gradually with age. These changes can cause reduced muscle coordination, slower reaction time, and impaired mental functioning.

Reproductive System - Some physical changes occur in old age. After menopause, women experience little change, most commonly vaginal drying. For men,

erections may require more stimulation and the prostate may become enlarged. Regular medical check-ups are important for both genders.

Despite these changes, the majority of persons age 65 and older continue to have both interest in, and capacity for, sexual relations. Among the factors that **may** inhibit sexual activity among the elderly are poor health, boredom with a partner, lack of a partner, and social taboos and stereotypes.

The Senses - We all rely on sensory perceptions, constantly gathering information about the surrounding environment which enables us to function. As people grow older, significant changes occur in the various sensory abilities. Less sensory information is conveyed to the brain, resulting in a lack of awareness and/or misperceptions of environmental stimuli. In addition, the central processes of the brain that are responsible for interpreting sensory information progressively slow down. Consequently, older individuals take more time to process and react to sensory information:

Sight - Changes can include development or worsening of nearsightedness or farsightedness, reduced ability to adjust to changes in the intensity of light or darkness, decreased ability to focus at varying distances, reduced depth perception, impaired side vision, and declining ability to distinguish colors. There is a decrease in the water in the eyes that can lead to dry eyes, a painful condition. The cumulative changes in sight can alter a person's sense of independence and self-confidence. In a familiar environment, a person may function well because he/she knows where everything is and how things work. However, in an unfamiliar environment the person may appear confused, disoriented and slow.

Hearing - Most people experience a gradual loss of hearing throughout their lives. Eighty-eight percent of the elderly have some degree of hearing impairment, with one of the most common impairments being the inability to hear high-pitched tones. Other impairments are difficulty hearing sounds of normal or low volume and distortion of the sounds that are heard. Hearing loss is potentially the most problematic sensory loss. Individuals who have some degree of hearing loss may not realize that they have a loss, resulting in misunderstandings. Moreover, people with hearing loss may hear only part of what is said and respond inappropriately, causing embarrassment.

They may feel isolated and alone, may withdraw from social situations (especially groups), may begin to think that others are talking about them, and may lose access to sources of entertainment such as television and radio. As a result, they may become depressed.

Taste and Smell - Taste and smell become less sensitive with age. Many older persons complain that food taste bland, and they may experience a loss of appetite or may use excessive amounts of such seasonings as salt and sugar. In addition, the aged may be oblivious to certain odors, even body odors.

Touch - There is a decline in sensitivity to temperature, pressure and vibration, particularly in the feet and legs. Sensitivity to pain also is reduced.

Health Issues

Most older persons have at least one chronic condition and many have multiple conditions. Among the most common diseases in old age are arthritis, heart disease, elevated blood pressure and diabetes.

Prescription Drug Misuse/Abuse a Health Threat to the Aged - As the aged experience more health problems, medications play a larger role in their lives. Many elderly persons experience such drug-related problems as adverse reactions to medications and the misuse or abuse of medications.

As we age, the kidneys filter the blood less efficiently, causing medications to remain in the bloodstream longer than for younger people. This change compounds the danger of over-medication. Dosages of medicine need to be closely and continuously monitored. Interaction effects between prescribed medicines and over-the-counter drugs, even aspirin or Bufferin, also are more likely to occur.

Medications can cause mental health problems, as well as cognitive or functional problems. For example, apparent symptoms of dementia actually can be caused by medications

Caveat

All of the aging-related physical changes and issues we have been discussing represent general tendencies for elderly people that vary widely between individuals. Moreover, most older adults adapt well to these changes and function well enough to meet their own needs.

Selected Social and Economic Aspects of Aging

During old age, people tend to experience a great many social and economic changes, such as the death of loved ones, retirement and the loss of social roles (e.g., spouse and worker/provider. Nevertheless, family and friends remain important in the lives of older adults. Another difficult change is the loss of a long-time residence, sometimes followed by moving into a long-term care facility.

Mental Aspects of Aging

Thinking Abilities

There are many common myths about declining mental functioning in old age. The truth is that there is little innate biological reason for a serious decrease in mental ability solely as a consequence of aging. While there is a normal gradual decline in the ability to remember a recent event or idea as we age, such memory changes are limited and do not have a major impact. Vocabulary, judgment and the ability to draw on experience increase with age, while the ability to use words, follow directions and solve problems continues unabated.

Like anyone else, older adults can use notes and reminders to help them remember. Significant memory loss or other impairments in mental functioning in older adults are not a normal part of aging.

Dementia: Serious impairment in the mental functioning of persons of any age is referred to as "dementia." Dementia includes such symptoms as significantly impaired memory, judgment and thinking abilities; personality change; and disorientation as to where a person is, who people are and what time/season it is.

Irreversible dementia develops as a result of damage to the brain, while reversible dementia-like symptoms can develop from other, treatable causes like dehydration, certain acute illnesses, environmental changes, medications and depression.

It should be remembered that reversible conditions can unnecessarily reduce anyone's functioning.

We should not assume that an elderly person has dementia just because he or she seems confused. Consequently, we must be careful about labeling elderly persons. People, including health professionals, may accept a label and not pursue appropriate diagnostic tests and treatments. Instead, a person's behavior should be objectively described.

The incidence of Alzheimer's disease increases with age, but Alzheimer's disease--and dementia in general--is not a part of the normal aging process. It has been estimated that less than ?% (stats will be included later) of persons under age 65 have Alzheimer's disease. Overall, about ?% (stats will be included later) of persons age 65 and over suffer from Alzheimer's disease. Again, Alzheimer's disease is a disease that becomes more common with increased age. It is not part of the normal aging process.

During the course of Alzheimer's disease (which may last many years), the person eventually is likely to become:

- unable to carry out everyday functions and activities
- unable to communicate effectively
- unable to recognize family members
- a danger to him/herself.

Because of memory loss and poor judgment, a person with Alzheimer's disease needs to be watched constantly and protected from wandering into danger. People with Alzheimer's disease also often adopt behaviors that disturb other residents, families and staff (e.g., wandering, screaming, repeating questions, rummaging and aggressiveness).

To meet the special needs of people with Alzheimer's disease, some nursing homes have special wings that structure resident activities and monitor behavior and needs. These "special units" vary in the extent to which they modify the environment and programming to best serve residents with Alzheimer's disease

Reversible Dementia-like Symptoms: Reversible or treatable conditions also can cause dementia-like symptoms. Among these conditions are high or low body temperature, dehydration, inadequate diet, vision/hearing problems, a new environment, physical problems like pain or constipation, medications and depression.

Emotional Health

As a group, the elderly are as emotionally healthy and almost as satisfied with life as younger adults. Nevertheless,?% of the aged suffer from moderate to severe psychological disturbances. The most common psychological problems of older adults are depression, anxiety, thoughts of suicide, substance abuse and paranoia.

Change and Losses: As we have discussed, people experience change and losses throughout their lives. However, older adults experience a wide array of changes and "as a group are in a state of transition."[4] In old age, the most common potential losses, retentions and gains have long been recognized and can be described as follows.

[4] Schlossberg, Nancy. (1979) "Adaptation of Older Adults: A Transition Model." in Mary L. Ganikos (Ed), **Counseling the Aged: A Training Syllabus for Educators**. Falls Church, VA: American Personnel and Guidance Association. p. 89.

Most Common Potential Losses, Retentions and Gains in Old Age[2]

Most Common Potential Losses	Most Common Retentions	Most Common Potential Gains
Physical		
Health	Work Productivity	Work Morale, Loyalty
The Senses	Social Awareness	Less Supervision
Reaction Time	Nurturing	Less Job Absenteeism
Physical Abilities	Aestheticism	Less Job Turnover
	Children	Fewer Job Accidents
		Higher Job Satisfaction
		More Free Time
		Higher Frustration Tolerance
		Cautiousness
		Maturity & Experience
		Need for Achievement
		Responsibility
		Reliability
Social		
Employment	Thinking Abilities	
Income	Old Learning	
Time Structure	Immediate Memory	
Social Status	Long-Term Memory	
Parents, spouse, friends	Personality Traits	
Roles and Activities		
Psychological		
Independence	Adaptability	
Identity	Creativity	
Body Image	Sexuality	
Sense of Usefulness	Coping Abilities	
	Steady Work Habits	

[1] Derived from: Sinick, Daniel. (1979) "Adult Development Changes and Counseling Challenges" in Mary L. Ganikos (Ed), **Counseling the Aged: A Training Syllabus for Educators**. Falls Church, VA: American Personnel and Guidance Association. p. 34.

Some changes and losses are more difficult to cope with than others, and some losses may be more serious in their impact than one might expect. For example, seemingly unimportant objects which are representative of special relationships or of personal achievement may be particularly important to an older person. Losses and changes also are interconnected. Retirement or physical impairments may force a loss of roles, responsibilities and activities that once gave meaning to a person's life. Opportunities to make new friends, to acquire new skills, or to accomplish life-long goals also may be eliminated or greatly restricted. All of these gains, losses and other changes are transitions with which older people must cope.

Reactions to change vary from person to person at all ages. Sometimes older people are seen as resistant to change, or "set in their ways." However, their refusal to accept change is their way of maintaining control. To say, "No" is to keep one area of their lives stable. At other times change may be refused because it may not be understood. More information or different words may be needed to clarify the explanation of the change, even if it is about a service being offered. Older people may need more time to consider the proposed change, to think it through, to decide. To have assurance that the change can be tried on a temporary basis and then reevaluated may encourage a person to accept change. There may be a very good reason for saying," No". They need to be listened to in order to understand their needs. Change, whether positive or negative, is stressful. All individuals need time to adjust.

Some Reactions/Issues You May See in Older Persons:

- **Loss Reaction** - Tendency to talk about the many losses that have been experienced. There are two primary reactions to loss: anger and grief. Both are natural and may be expressed in various ways depending on the individual. Talking about the loss is a therapeutic way to grieve, come to terms with, and accept the loss.

- **Life Review** - Spending time reflecting and reminiscing about life experiences.

- **Fear of Losing Control** - Expressing fear of decline of physical and/or mental powers and becoming dependent.
- **Fear of Death or Being Alone Late in Life**
- **Somatic Concerns** - Complaining of physical ailments or recounting detailed histories of bodily functions.
- **Cautiousness** - Exhibiting little confidence in making appropriate responses, placing high value on accuracy and the avoidance of mistakes.

Death and Dying

One powerful form of loss is death and dying. Although death and dying may trigger strong feelings and negative thoughts, it is a natural part of the life cycle. There are five major reactions to death or dying that have been identified by researchers: denial, anger, bargaining, depression, and acceptance. People do not always experience every stage, nor do they always experience the stages in the sequence indicated. Stages may be repeated or skipped.

Families or friends may experience these reactions just as individuals who are dying experience them. The reactions of families or friends may not be parallel to those of the patient. They may be in different stages at the same time. Let's look at descriptions of the stages, along with indications of appropriate responses.

Responding to Death and Dying[3]

Responses of the Dying	**Role of the Ombudsman and Caregiver**
Denial:	
When the awareness of a serious or fatal illness comes, persons react with shock and denial: "No, not me! It can't be me!" "This is not really happening. Someone has made a mistake."	Listening is very important. The dying person may not talk much and should not be pushed. The resident should be allowed to daydream about happier things regardless of how improbable these may seem.
Anger:	
When denial can no longer be maintained, anger takes over. The question becomes "Why me?" or "Why did God let this happen to me?" The person feels angry, bitter and envious of others who aren't dying.	Family and friends usually find this stage difficult and mistake the anger as a personal attack. Be careful not to shorten or avoid visits or to react with anger. The resident needs an opportunity to ventilate his/her feelings. If the person feels respected and understood and is given attention by those important to him/her, he/she may soon begin to reduce the angry demands.
Bargaining:	
The person hopes that if he/she carries out promises, he/she will be rewarded with a longer life. This postponement is expressed in the hope that he/she will live to see some special event. "Yes me, but..." many of these bargains are made with God and may be kept secret from family or friends.	The resident needs someone to listen to him/her and to recognize his/her feelings. Ventilation of fears often helps to relieve the resident's feeling of guilt and enables the person to work through this stage in a more satisfying manner.
Depression	
Faced with the reality of such a great loss, the person is profoundly sad.	Our initial reaction to depression is to try to encourage the person to look at the bright side. This approach, however, can be an expression of our own needs, and is not generally helpful in working through this stage. In dealing with reactive depression, the individual may have much to share. Listening is very important. The resident experiencing depression will often express his/her sorrow through silence. In these instances, a touch of a hand or just silently sitting together is usually more meaningful than words.

Acceptance	
If the person has had sufficient time and the support and care of those around him/her, he/she will pass into a stage of acceptance of impending death: a calm, peaceful and comfortable readiness to face death. The person is not happy, but not terribly sad either.	The family may need more support than the dying person, who has already found some peace. It is a silent time in which the resident wishes to be left alone. He/she often prefers that visits be short and relatively silent. Our presence confirms that we will be around until the end and reassures him/her that he/she is not alone. Evening visits may be best for this stage because there will probably be fewer interruptions.

[3] Adapted from Elisabeth Kübler-Ross's work on death and dying.

Populations in Nursing Facilities

Now that we have looked at the normal aging process, we are going to discuss long term care facility residents and their families.

A majority of nursing home residents are without a spouse in addition, nursing home residents tend to have health problems that significantly restrict their ability to care for themselves. The absence of a spouse or other family members who can provide informal support for health and the inability to care for oneself are the most critical factors in the institutionalization of an older person. Let's look at a profile of the "typical" resident.

- They are generally very old. (over 75 years of age and older)
- They are generally female.
- Most are single.
- Most are Caucasian.
- Many suffer from behavioral or mental disorders.
- Most have chronic or crippling disabilities and need help with the activities of daily living (ADLs), including assistance with bathing, dressing or eating.

It is likely that the nursing home population will continue to grow rapidly, partly because of the growth in the size of the very old population, and partly because of the increasing gap in life expectancy between husbands and wives

Populations in Assisted Living Facilities

Since little data is available on the residents of Arizona's Assisted Living Facilities, we will look at the populations of assisted living facilities nationally. The needs, preferences, and characteristics of assisted living home residents vary between homes. Some assisted living homes serve only elderly individuals; others have a mix of mentally ill, developmentally disabled and elderly residents.

The two largest categories of residents in assisted living homes include older women, particularly those who are widowed or single, and older people with functional limitations. But older adults are by no means the only beneficiaries of assisted living homes. In many areas of the country, large numbers of mentally and developmentally disabled persons are being released from mental hospitals, veterans hospitals, and nursing homes into `less restrictive' community-based facilities, including assisted living homes, where they can continue to receive mental health care or other needed services on an out-patient basis.[5]

The Long Term Care Experience

Why are some elderly individuals admitted to long term care settings? Generally, there is a gradual progression of losses, diminution of strengths, decreasing opportunities for meaningful and restorative personal and social experiences, and increased isolation. As self-sufficiency decreases, there is less opportunity for continued living in the community. Communities often don't have adequate services to provide those supports and opportunities which once came from the family and the neighborhood. Generally, the family, the community agency or a hospital (through the physician and social workers) step in and decide that the older people can no longer adequately care for themselves or be cared for in the community. When a long-term care institution or nursing home is chosen as an alternative, it is often the only option.

[5] Dobkin, L. 1989. *The Board And Care System: A Regulatory Jungle*. Washington, D.C.: American Association of Retired Persons, 2.

The transition that the elderly (and their families) face when an older adult moves from a community setting to an institutional setting is a difficult one. Some of the problems of older residents (e.g., physical disabilities or deterioration) do not start with admission into the long-term care setting, but are pre-existing.

Other problems facing the new resident arise because of the nature of the setting itself and how services are delivered within an institutional setting.

Adjustment to Institutionalization

The move from community to a long-term care setting is a major life event for both resident and family. It is important to consider this stress in adjusting to a new setting, both for the resident and his/her family.

Residents: Some residents in long-term care facilities may have difficulty adjusting to life in an institution. A move from the community to an institution often means many changes in lifestyle, including: set routines for meals and for getting up and going to bed; a decrease in contact with the community; more free time with structured activities available only at certain times; decreased privacy and independence; fewer opportunities for decision-making; loss of home, many possessions and links to the past; increased loneliness; and the need to adjust to staff and other residents. Normal reactions to these changes include anger, depression, grief, confusion, and withdrawal.

Residents should be encouraged to state their opinions and preferences, and should feel free to voice any concerns they might have. Many persons are eventually able to make a successful adjustment to institutional living. Persons who live to old age have weathered many changes throughout their lives. As a result, they are often more resilient and capable of adjusting to loss than are younger adults.

Although physical needs may be more than adequately met in an institutional setting, older persons' belief in themselves as worthwhile may be threatened. Therefore, it also is important to meet psychological needs including:

- The need to be seen by others as an adult who has had a lifetime of experience.
- The need to have others recognize one's uniqueness.
- The need for respect and approval from others.
- The need for self-confidence.
- The need for positive interaction with others.
- The need to preserve one's sense of identity and individuality.
- The need for emotional support.
- The need for as much control as possible over one's environment.

Many of the problem behaviors exhibited by nursing home residents arise from these needs not being met.

Being a resident of a long-term care facility does not mean one surrenders all of his/her rights. It also does not mean one becomes totally dependent upon others for care. Staff may inadvertently encourage dependency because it is easier and faster for them to care for the residents than to allow time for the residents to do things for themselves. The residents who doubt their self-worth because of a move to an institution may give up trying to do anything independently. Because they believe that nothing they do matters, they make no effort to control their environment. Such "learned helplessness" may be discouraged when residents are given the opportunity to make choices and are encouraged to do things for themselves. Studies have shown that nursing home residents' life satisfaction improves when they are given the chance to make more decisions, even when they are not major decisions. Little things like choosing one's own clothes or desserts can vastly improve a resident's adjustment to the facility.

Family: For persons in long term care facilities, family and friends can be particularly important. Consequently, residents' family relationships and friendships are important for ombudsmen, since you will be working with both long term care residents and their families. Two critical points to remember are:

- Family relationship patterns established in earlier years tend to continue.
- A move into a nursing facility definitely impacts both family relationships and friendships.

Role reversal with family, as well as caregivers, is a common "danger" for older adults. While it is true that an elderly person may become more dependent, that person is still an adult. It should be remembered that dependencies in one area do not mean a person is dependent in all areas. An individual may need help with dressing or assistance in planning, but this does not mean that he/she needs someone to make financial decisions for him/her. A person may require temporary assistance in managing personal affairs until he/she recovers from an illness or stress and is able to assume total responsibility. Sometimes families or caregivers decide an elderly person is incapable of independence simply because the person makes a decision which disregards their advice.

Sometimes older individuals may act like children because they feel they are being treated as children. They are responding to ***our*** expectations. Older people need to be encouraged to do as much for themselves as possible. Caregivers should patiently allow sufficient time for individuals to respond to questions or to accomplish tasks. The emphasis should not be on perfection but on personal accomplishment. Reinforce the decision-making ability of the elderly person. Sometimes older people themselves believe they are incapable of exerting independence and need encouragement to exercise choice. Even when families or caregivers must assume some decision-making on behalf of an elderly person, that older adult needs to continue to be treated as an adult.

The family also must make adjustments to a family member living in a long-term care facility. Usually the placement of a relative in a nursing home leaves the family with a mixture of feelings. They are likely to feel relief that the ordeal of selecting and choosing a nursing home is over, that the emotional storm raging around whether or not to put the relative in the nursing home has finally been resolved.

But in addition to relief, feelings of guilt may also play a major part in how the family reacts to the resident and the nursing home situation. No family enjoys having to place their relative in an "institution," no matter how nice a place it may seem to be. The family usually feels as if it could have prevented the situation from going as far as it did, either with the deterioration of the resident's physical condition, or the emotional strains that were placed on everyone involved. As individuals, they may feel self-accusatory, blaming themselves and each other for not doing "more" to help cushion the effects of aging, or take (or keep) their parents at home with them. The sense of helplessness which underlies the family's inability to cope with the needs of the aging will have become pervasive by the time the relative has reached the nursing home.

Expressions of family guilt may be acted out in a number of ways--possibly in the way the family speaks to the resident, in an angry, babyish, or child-like manner; in the insistent demands it makes on the nursing home staff; or in staying away from relatives altogether.

When relating to residents' families, ombudsmen should be aware of the following:

- When relatives "complain," they may be more upset with themselves than with nursing home personnel.
- Many relatives feel guilty that they were unable to care for the resident themselves, perhaps due to physical reasons (size of home) or psychological reasons (unable to tolerate a sick and dependent parent) and have had to allow someone else to assume "their" responsibility.

Selected Illnesses and Conditions of the Elderly in Long-Term Care Facilities

Many older adults in long-term care facilities have certain illnesses and conditions. Among the more common of these are:

Malnutrition: A person suffering from malnutrition has little energy and in the advanced stages is often mentally confused. Poor eaters are at risk, in part, because of the limited protein reserves in the body. Causes of malnutrition include:

- Eating alone after the death of a spouse
- Depression
- Reduced sense of taste due to the effects of aging, smoking and/or medications
- Diminished absorption of nutrients due to aging-related changes
- Poor-fitting dentures. Shrinkage of the jaws can cause dentures to fit improperly.
- Not enough saliva. (Saliva aids in breaking down food in the mouth.)
- Reduced ability to swallow (known as dysphasia).
- Refusal to eat as rebellion. Some individuals may be angry with relatives for placing them in a nursing home or seemingly abandoning them. They also may be angry about being sick, angry at their doctor or angry at staff.
- Inadequate assistance during mealtime or not allowing enough time to eat with cues and encouragement.

It can be difficult for staff and relatives to cope with refusal to eat. They may become frustrated and resentful, causing a repetitive cycle of further resistance from the resident and retaliation from the nursing home staff.

Hiatus Hernia: Hiatus hernias are protrusions of the stomach upward through the esophageal opening of the diaphragm. Symptoms include heartburn, indigestion and reflux of gastric contents. Staff may not realize that these symptoms can be minimized by being sure that the resident:

- sits up straight while eating,
- eats smaller, more frequent meals of bland, easily digested food, and
- sleeps with the upper part of his/her body in a raised position.

Constipation: The most common digestive problem among bedridden or inactive people is constipation. Constipation can be caused by:

- Lack of fiber and/or fluid intake
- Decreased muscle tone
- Ignoring or being unable to heed the normal urge to defecate
- Laxative abuse. Many older people are dependent on laxatives. If a person uses laxatives for any length of time, their digestive system will become unable to function without them. Excessive use of laxatives also impairs the absorption of fat and fat-soluble vitamins.
- Prolonged bed rest
- Insufficient food intake
- Tumors
- Certain medications, primarily sedatives, tranquilizers, narcotic pain killers and antacids

Residents may complain about or have such symptoms as:

- Abdominal pain
- Distention (stretching or enlargement) of stomach
- Cramping

Extreme constipation can become a medical emergency. It also can cause mental confusion as the system becomes poisoned by waste products that cannot be eliminated. Treatment of constipation may include a hearty breakfast, six or more glasses of water per day and moderate exercise. A person who is dependent on laxatives needs to be taken off them gradually under a physician's supervision.

Dehydration: Water accounts for more than half of body weight. Fluid that is lost every

day in normal body functions is usually replaced. When fluid intake is insufficient or output is excessive, there is too little water in the body. This is called dehydration. The symptoms of dehydration include:

- Sunken eyes
- Dry tongue
- Dry skin
- Cracks in the corners of the mouth
- Loose and less elastic skin
- Signs of confusion

Having water available at all times is imperative to the health of residents. Since older people cannot hold as much water, they need to drink more frequently. Moreover, many residents cannot drink by themselves or cannot reach the water left on their night stand. Some residents (at times with the encouragement of staff) do not drink water late in the day to avoid getting up at night. Sometimes, an older person may not feel thirsty even though he/she is dehydrated. Overcoming these barriers to proper hydration is critical, especially in Arizona, and requires active efforts by staff.

Osteoporosis: Osteoporosis refers to a loss of calcium from bones that causes increased bone brittleness and can result in fractures. It is responsible for over 5 million spontaneous fractures every year, and 55,000 people die annually from osteoporosis-related fractures. Osteoporosis affects more women than men, especially older white women. It results from an insufficient calcium intake and a lack of exercise.

An older person's activity level may decrease significantly following admission to a nursing facility, accelerating calcium depletion.

Parkinson's Disease: Parkinson's Disease is an incurable, degenerative and progressive disease of the central nervous system. It is characterized by tremors in the extremities, rigidity and slowness of movement. Among the symptoms of Parkinson's Disease are:

- Poor grasp
- Poor mouth-hand coordination
- Inability to suck or close one's lips well
- Limited ability to bite, chew and swallow

  As the disease progresses, the resident will need frequent help with eating and drinking. The resident also may need special utensils, a special diet and extended time to eat.

Myths and Realities of Long-Term Care

We have discussed some common generalizations, and realities, about older people. Some of these have been discussed in the preceding sections of this module. Stereotyping and myths also affect the medical treatment older individuals receive and the way caregivers treat them. As an ombudsman, you must be aware of these myths and be able to ask questions and offer information at opportune moments. You need to know what conditions indicate a need for more assessment and/or consideration of different treatment interventions rather than assuming that the conditions are simply manifestations of the aging process.

Since your job will be working with individuals in long-term care facilities, we will now focus on issues in that environment. The same principles are applicable for individuals in home settings or in residential care facilities.

Basis for Rethinking Stereotypes about Long-Term Care[6]

It is important to challenge long held perceptions about the causes of decline in old age and about appropriate treatment. Increased knowledge about aging and the elderly has highlighted many errors that unnecessarily limit older people. In addition, there is a solid legal basis for rethinking stereotypical responses.

The Nursing Home Reform Law (OBRA '87) challenges the mind-set of:

[6] Most of this section is based on *The Promise Of Nursing Home Reform Is In Your Hands....An Advocate's Message to Surveyors*. B. Frank, *Survey & Certification REVIEW*. June 1992, pp.3-8.

- *This is the way we've always done it*.

or

- *We don't have the staff to do it.*

OBRA '87 challenges everyone to re-examine assumptions and practices, such as:

- Old people are hopelessly depressed.
- Pressure sores and incontinence are unavoidable.
- Residents must be controlled by restraints.

Some practitioners have blazed the trail: finding that time spent on thorough assessment and care planning saves time in the long run; accommodating individual needs and finding it more efficient to do so; and replacing restraints with better care. Their experience shows the law's potential.

Quality of Care under OBRA requires that:

> *A nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident in accordance with a written plan of care...*

The requirements for long-term care facilities explain what Quality of Care means:

> *Based on a comprehensive assessment of a resident, the facility must ensure that a resident's abilities in activities of daily living do not diminish unless circumstances of the individual's clinical condition demonstrate that diminution was unavoidable. This includes the resident's ability to bathe, dress and groom; transfer and ambulate; toilet; eat; and use speech language or other functional communication systems.*

The regulation applies to vision and hearing; pressure sores; urinary incontinence; range of motion; mental and psychosocial functioning; naso-gastric tubes; etc. This says that people should not get worse because of the care they receive in the nursing home; in fact they should reach the highest level of functioning and well-being that they are capable of achieving. If a resident was able to walk, or transfer, or bathe herself, or move her arms, or maintain her skin condition when she entered the facility, she should still be able to do so six months or a year later and for the rest of her stay in the facility, unless circumstances of her clinical condition demonstrate diminution was unavoidable.

The following is a description of some common myths and stereotypes that are being proven untrue. The Resident Assessment Protocols (RAP), part of the mandatory resident assessment process completed on admission to a skilled nursing facility, contain excellent guidance to assist in changing perceptions and treatment approaches for all of the conditions in this section. The knowledge basis and educational resources are available to alter *the way we've always done things.* As we change our way of thinking about conditions, there will be dramatic differences in what happens to individuals who enter nursing facilities.

Loss of Mobility

Myth or Stereotype: Nursing home residents may not be capable of walking or moving. Given their frail condition, movement is not as important for residents as it is for other adults. They will experience a decline in mobility as an inevitable part of growing older.

Reality: Movement, like other basic human needs, is lifelong and doesn't end with old age and institutionalization. The ability to meet these needs may fluctuate with physical and mental ability, but the drive that initiates the pursuit is forever. Frail elderly who enter nursing facilities retain the drive to meet their need for movement, just as they do for the other basic needs. Institutions often fail to assist residents in meeting movement needs because they fail to recognize movement as a basic human need.[7]

All individuals need to move. Impaired mobility can lead to a number of harmful physical and mental complications, which, taken to their extreme, can be fatal.[8] Immobility negatively affects every body system.

[7] Mobility: A Basic Human Need, Quality Care Advocate Special Section. T. Tempkin. National Citizens' Coalition for Nursing Home Reform. Washington, D.C. 1993, p.i.

[8] Ibid., p.i.

In a limited study of nursing home residents, residents who walked outdoors reported less fatigue than residents who did not walk outdoors.[9] Residents in the walking group slept better and reported better appetites than others in the study. Mobility is essential to life. It impacts more aspects of life than just the physical ability to move.

Pressure Ulcers

Myth or Stereotype: Due to the age related changes in the skin and the frailty of nursing facility residents, pressure ulcers/sores are inevitable for individuals who are not independently mobile. Pressure sores are an unfortunate part of normal aging for frail elderly.

Reality[10]: A pressure ulcer is an injury primarily caused by unrelieved pressure that damages the skin and underlying tissue. They are serious problems that can lead to pain, longer hospital or nursing home stays, slower recovery from health problems, and even death.

The prevalence of pressure ulcers in residents in nursing homes is approximately ? %. Individuals who are at risk of developing pressure sores are persons with limited mobility, incontinence, debility, decreased mental states, confusion or apathy.[11] ***Almost all*** *pressure ulcers can be prevented.*

Interventions include early detection, turning residents in bed frequently (e.g., every two hours), ensuring adequate nutrition, using pressure reducing mattresses, and attending to environmental factors that lead to skin drying such as low humidity (less than 40 percent) and exposure to cold. Assessment needs to include mobility, nutritional factors, hydration, continence, and level of consciousness.

Urinary Incontinence

[9] Outdoor Walking Lowers Fatigue. S.H. Gueldner & J. Spradley. Journal of Gerontological Nursing. Vol.14, No. 10, pp. 6-12.

[10] Most of this section is from *Clinical Practice Guidelines No.3: Pressure Ulcers in Adults: Prediction and Prevention*. U.S. Dept. of Health & Human Services, Public Health Service, Agency for Health Care Policy and Research. Rockville, MD: May 1992.

[11] Positioning and Skin Care, Practical Rehabilitation Techniques for Geriatric Aides. R.L. DiDomenico and W.Z.Ziegler, Aspen Publishers, 1989, p.73.

Myth or Stereotype: Urinary incontinence is to be expected, especially among residents in nursing facilities. It is another signal of advanced age and physical decline. Once it occurs there is nothing that can be done except to keep individuals clean and dry.

Reality: Contrary to myth, incontinence is not a normal part of aging, is actually easier to treat in the elderly than in those who have incontinence when young, is not inevitable even in those with dementia and is manageable in one-third of those with dementia.[12] Urinary incontinence is the involuntary loss of urine which is sufficient to be a problem for the individual. It is estimated that at least one half of all nursing home residents experiences urinary incontinence. Urinary incontinence is a symptom rather than a disease.

In some cases the disorder is temporary, secondary to an easily reversed cause such as a medication or an acute illness like urinary tract infection.[13] The most probable cause of urinary incontinence is immobility from chemical and physical restraints. Many cases last indefinitely unless properly diagnosed and treated.[14] Incontinence not only affects skin conditions and care routines but also has a profound affect on an individual's dignity, self-esteem, and social relationships. Minimizing risk factors and a thorough assessment and appropriate interventions are essential to helping individuals maintain, or regain, urinary continence. Restorative care is important.

[12] The Nursing Home Incontinence Project. D. L. Siegal, Prepared for Living is for the Elderly, Jan.1992.

[13] Urinary Incontinence in Adults. National Institutes of Health Consensus Development Conference Statement. Vol. 7, No. 5. Oct. 3-5, 1988.

[14] Sarah G. Burger, National Citizens' Coalition for Nursing Home Reform, in a telephone conversation, January 14, 1994.

Depression

Myth or Stereotype: Older individuals tend to withdraw, to slow down, and to become depressed. Sadness is a natural response to loss of physical abilities and other life stage changes; therefore, depression is a normal part of living to an advanced age.

Reality[15]: The ability to think, to feel, to interact with others, to share a sense of purpose, to work, to love, to experience gratification, to care for others, and to maintain self-responsibility are precious human attributes that elderly people strive to maintain. In few circumstances are these elements of our experience and capacity so broadly and deeply challenged as with depressive disease.

Depression in the elderly is under diagnosed and under treated. A depressed mood may not be as prominent a symptom among the elderly as symptoms such as: loss of appetite, sleeplessness, inactivity and loss of interest and enjoyment of the normal pursuits of life. Depression affects many aspects of an individual's life. One study suggests that a result of not treating depression in the elderly is a heightened risk of death.[16]

Treatment is effective and depression can be alleviated in many cases. Proper assessment, detection, and intervention are critical.

Safety Concerns

Myth or Stereotype: As individuals become older and more physically frail, they need to be protected. Safety becomes very important; thus, minimizing risk is desirable. Using restraints is sometimes necessary to keep individuals from harming themselves by falling or other actions that could be detrimental to their health.

Reality: Life continues until death. Throughout life, individuals live with risks, all of life has risks. It is impossible to create a totally risk-free, 100% safe environment.

---

[15] Much of this section is taken from *Diagnosis and Treatment of DEPRESSION In Late Life*. Consensus Statement. Vol. 9, No. 3, National Institutes of Health. Bethesda, MD. Nov. 4-6, 1991.

[16] High Death Risk Is Found in Depressed Nursing Home Patients. D. Goleman. New York Times, Feb. 27, 1991.

Some of the care practices that have been justified on the basis of safety may need to be questioned. Physical restraints do not make people safer. In fact, restraints are often harmful.

Caregiver experience and medical research now show:

> *When a person stops using a body part, that part no longer works very well. The old saying, "use it or you'll lose it," is true — people who are able to get up to try to walk and are restrained become weaker. Also restrained residents often try to get out of restraints, sometimes resulting in serious injuries such as: broken bones, cuts requiring stitches, concussions.*

Some people also fall if they are not restrained. But research shows that these residents, when they do fall, have less serious injuries than those who are restrained.[17]

In talking with residents, families, and nursing home staff, it is important to remember that individuals have the right to take risks as long as they have enough information to allow them to make an informed decision. Advanced age does not remove an individual's ability to accept risks.

Summary

In spite of common misperceptions about the consequences of normal aging, good clinical practice is debunking the myths. Individuals don't have to develop pressure ulcers, incontinence, or become immobile or depressed. Even if these conditions/symptoms develop, treatment may turn them around if begun early enough and in an effective manner. The Quality of Care and Quality of Life standards of the Nursing Home Reform Law are attainable. They can be reality for each individual living in a nursing facility!

[17] Avoiding Physical Restraint Use: New Standards in Care: A guide for residents, families, and friends. Burger, S.G., National Citizens' Coalition for Nursing Home Reform. Washington, D.C.: 1993, p.7

MODULE III

LONG-TERM CARE SETTINGS

MODULE III: LONG-TERM CARE SETTINGS	

Learning Objectives:

1. To be aware of the historical development of long-term care in the U.S.

2. To understand basic facts about nursing homes including types, ownership, industry associations, departments, staffing, services, special programming, reimbursement sources and basic regulations.

3. To understand basic facts about assisted living facilities including types, ownership, staffing, services, reimbursement sources and basic regulations.

Module III: Long Term Care Settings

OUTLINE

Introduction to Long Term Care Settings

Long term care facilities assist aged, ill or disabled persons who can no longer live independently. In this module, we will briefly examine the history of long term care facilities in the U.S., as well as the characteristics, staffing, services, ownership, funding and regulation of nursing homes and adult care homes.

Historical Overview[18]

Long term care facilities have gone through several stages of development to become what they are today. Forerunners of these facilities were *almshouses* or *poorhouses*, which were run by municipalities, churches, or philanthropic organizations as a way of collectively meeting the needs of those who could not provide for themselves, including the aged, handicapped and homeless. The roots of long term care in the almshouse, poorhouse, or "county poor farm" has given long term care facilities a strongly negative connotation for many elderly people.

The Social Security Act is indirectly responsible for the nursing home industry as it exists today. Social Security provided Old Age Assistance (OAA) to needy people aged 65 and older who live in the community. The Social Security Act prohibited Old Age Assistance money from going directly to residents in public institutions. This signaled the beginning of the end for the public poor houses and contributed to the need for new alternatives for the aged without families who could care for them. Between 1935 and 1960, private rooming houses, private institutions, church-sponsored and other nonprofit institutions and homes flourished and were paid for by the residents' Social Security money.

As a result of scandals that received considerable publicity, states and local governments began developing licensing standards and procedures. Moreover, in 1950 amendments to the Social Security Act extended OAA to residents of public medical institutions. These amendments also required states to establish standards and a licensing agency for nursing homes. This gave official status to nursing homes as facilities to provide long-term care.

[18] Much of the information in this section is from the “Statistics” chapter of *The Ombudsman Desk Reference*. The National Center for State Long-Term Care Ombudsman Resources. NCCNHR. Washington, DC: 1993.

Dramatic changes followed the creation of the Medicare and Medicaid programs in 1965. The purpose of this legislation was to provide financial assistance to the poor and the aged so that they would receive adequate medical care, both in and out of an institutional setting. Due to the availability of federal funds to help pay for nursing home services, both the number of nursing home beds and the demand for these services greatly increased. The number of nursing home residents more than doubled from 1965 to 1980. The primary area of development has been in the proprietary (for profit) sector.

There are other important reasons for the great increase in utilization of nursing homes, including:

- Continuing breakdown of extended families in our society.
- An increasing older population, in both numbers and as a percentage of the total population.
- Medical advances extending the life span of older persons.
- Lack of government support for services to help older and handicapped persons to remain at home.

The nursing home industry in this environment grew dramatically with inadequate direction or regulation. Unfortunately, some opportunistic and dishonest operators gave the industry a bad reputation, creating a climate of mistrust and misunderstanding between industry and consumers that is still today. In 1987, a number of changes were made in federal regulations through the Omnibus Budget Reconciliation Act (OBRA '87). We will discuss more about OBRA '87 later.

Nursing home care in the United States has become an issue of major concern for older persons and their families and, indeed, for all persons.

Age is a major determinant of the need for these services. Although only about 5% of the elderly population are nursing facility residents on any given day, the probability of using nursing home services is high in this segment of the population.

Currently, there are more than (stats to be added later) nursing home residents in the United States

Nursing Homes

Types of Nursing Homes

There are two types of nursing homes in Arizona: licensed, and licensed and certified. The vast majority of health facilities in Arizona are licensed and certified.

- A **licensed nursing home** meets the licensure requirements of the State of Arizona and provides services as defined by the licensure agency (Arizona Department of Health Services).

- A **licensed and certified nursing home** meets all of the requirements of the State of Arizona and also meets the federal requirements for participation in Medicare and/or the Medicaid (ALTCS) Program. The distinction between licensure and certification is further discussed in the section on regulations.

Ownership and Management of Nursing Homes

Ownership and management of nursing homes is carried out by a variety of providers with an almost endless array of administrative and financial arrangements. However, long term care facilities can be distinguished by their type of ownership and their purpose. Some facilities are privately owned, while others are publicly (government) owned.

Privately Owned Facilities: Privately owned facilities are either proprietary or non-profit.

- **Proprietary Ownership:** The vast majority of long-term care facilities are proprietary, private businesses operated for profit. There are two basic forms of proprietary ownership: Individual/partnership and corporate.

  1) **Individual or Partnership** -- Profits are retained by individual owners or partners who are personally liable for a business' operation and debts and can be sued as individuals. This form of ownership is more common among adult care homes.

  2) **Corporate** -- Corporate stockholders or members are not individually liable for the corporation and cannot be sued for its actions or debts.

- **Non-Profit Ownership:** Non-profit long-term care facilities also produce profits, but these may not be legally distributed to individuals or groups for personal use. Instead, profits are returned to the general coffers of the organization. The primary financial goal of non-profit facilities is to increase their revenues. Many non-profit long-term care facilities are sponsored by religious, charitable or fraternal organizations.

- **Chains:** A long-term care chain is a popular name for a corporation (either non-profit or proprietary) that owns or operates more than one facility. These are usually privately owned through stock purchases.

Publicly-Owned Facilities: Some long-term care facilities, most commonly nursing homes, are government-operated. Such facilities are administered by county, state or federal governments. Veterans' nursing homes are included in this category.

Information on Ownership: Information on ownership of long-term care facilities is primarily available from the Arizona Department of Health Services.

Industry Associations

Many nursing homes belong to a professional trade association. In general these associations provide information, educational opportunities, and lobbying. In Arizona, there are two associations, the Arizona Health Care Association (AHCA) which is an affiliate of the American Health Care Association and the Arizona Association of Homes and Arizona Association of Homes and Housing for the Aging (AzAHA), which is an affiliate of the American Association of Homes and Services for the Aging. In general, the for-profit homes belong to the Arizona Health Care Association and the non-profit homes belong to the Arizona Association of Homes for the Aging.

Nursing Home Reimbursement

Who pays for long-term care? The increasing number of very old and frail persons, the rising costs of health care, and the availability of fewer family members to provide home care combine to make this question a major national concern.

Many of the people you encounter in nursing homes will be on Medicaid (ALTCS). Other sources of payment will include private pay, Medicare, Veterans Administration, and

private long-term care insurance.

Medicaid

Medicaid is a medical assistance program for low-income persons. It was established by Title XIX of the Social Security Act of 1965 and is a joint Federal-State program that reimburses providers for covered services to eligible persons.

The U.S. Department of Health and Human Services (DHHS) administers the program through CMS (Centers for Medicare and Medicaid). CMS establishes general guidelines and monitors operation of the program by the states. States are given some flexibility in deciding what services are covered and who is eligible, so there are differences in Medicaid from state to state.

Arizona's version of Medicaid is AHCCCS, the Arizona Health Care Cost Containment System. Within AHCCCS, Arizona's form of Medicaid for long-term care is called the Arizona Long Term Care System (ALTCS). ALTCS provides funding for nursing home care, home and community services and adult foster care. Alternatives to institutional care are offered so that the recipients who would otherwise be institutionalized may be treated in the least restrictive feasible environment.

Medicare

Medicare is actually multiple programs: Part A covers hospital and related care, Part B covers physicians and other medical expenses and Part D covers prescription drugs.

Medicare was established by Title XVIII of the Social Security Act and is administered by a number of agencies. The Social Security Administration handles eligibility determinations. CMS governs administration of the programs, and private insurance companies under contract with the government handle actual claims and payments.

Nursing Home Care -- Medicare covers skilled services (physical therapy, occupational therapy, skilled nursing services) following a qualifying hospital stay. Medicare pays for up to 20 days at full coverage and an additional 80 days at a set co-pay. One must meet the criteria for continued coverage. A beneficiary has the right to appeal the denial of skilled

care.

You may deal indirectly with Medicare when assisting a person admitted to the nursing home from a hospital. Under the Medicare Prospective Payment System, hospitals are paid based on a pre-set rate per case or type of diagnosis as categorized in Diagnostic Related Groups (DRGs). This system was designed to control costs and reward efficiency, but has sometimes led to patients being discharged in a weaker, sicker state. It is increasingly common for patients to move from a hospital to a nursing home, rather than returning to the community. This has been one factor, along with the overall aging of the population, in the changing character of nursing homes residents, who are generally older and sicker than several years ago.

Under contract with CMS, Peer Review Organizations (PROs) monitor the prospective payment system. PROs are physician-sponsored organizations with the authority to perform utilization and quality review functions for Medicare. They review diagnoses, appropriateness of admissions, and quality of care. A hospital's decision to deny admission or deny continued Medicare coverage can be appealed to the PRO.

Veterans Administration Benefits

The Veterans Administration (VA) Paid Community Nursing Home Care Program will pay for up to six months of skilled/intermediate nursing home care following hospitalization for those veterans who qualify.

Private Long Term Care Insurance

You may encounter a resident who has private long-term care insurance. As the demand for long-term care services have increased, insurance companies have begun to develop products that provide coverage for nursing home and or home health care. These policies are expected to account for an increasing percentage of long-term care financing, although most experts agree that they will never represent a major source of payment.
Most policies available are a form of "indemnity" policy, meaning they pay a set amount per day, week or month for care. There are tremendous variations in policies as to level of care covered, exclusions for certain conditions, renewal, deductibles, etc.

Selected Departments and Staff of Nursing Homes

Most nursing homes are relatively large institutions with fairly complex structures and equally large staff. While there may be differences between long-term care facilities, we will briefly review the structure and staff responsibilities of a "typical" nursing home.

Overseeing the total functioning of the facility is usually a governing body of some sort. The Governing Body has the overall responsibility for the operation of the facility, supervises the administrator, and sets facility policy and procedure for the health care and safety of residents.

The staff in a long term care facility are assigned to various departments, which are responsible for contributing to the overall functioning of the facility. It is important that the ombudsman become familiar with the nursing home's policies and organizational chart in order to understand the administrative lines of authority, responsibility and supervision. This will enable you to identify the appropriate persons when you need information from staff at a particular facility.

Administration: The administrative unit of a home may include the nursing home administrator, secretarial staff, accounting, and admissions.

- **Nursing Home Administrator** – responsible for overall (fiscal, legal, medical and social) management and operation of the facility. This individual is ultimately responsible for all nursing home activities, and must be licensed by the state

Medical Staff: Medical staff is responsible for attending to the physical needs of the residents. A variety of health care personnel are part of the staffing. Examples of these positions are:

- **Medical Director** -- the physician who formulates and directs overall policy for medical care in the nursing home. Usually only a part-time position.

- **Attending Physicians --** directly responsible for the care of resident. Each resident must either choose his/her own physician or have one assigned by their provider to supervise his/her care. This physician is not an employee of the facility but visits the resident as needed.

- **Podiatrist** – specializes in the diagnosis and treatment of diseases, defects and injuries of the foot. The podiatrist may visit the facility, usually on a monthly basis.

Nursing Services: The nursing services department generally includes RNs, LPNs, and nursing assistants. These are the people who provide most of the direct care to the residents. Examples of the nursing staff are:

- **Director of Nursing** (DON) -- a registered nurse (RN) who is responsible for establishing policies and procedures for the nursing staff, including nursing supervisors, licensed practical nurses and nurse aides. The DON is responsible for supervising the provision of all nursing care and thus for quality and safety in patient care. Usually considered second in command to the Administrator.

- **Nursing Supervisors** (also called charge nurses) -- supervise nursing (resident) care on a floor, or in an area or section, or in the nursing home during a particular shift. May be an RN or LPN.

- **Licensed Nurse** (LPN) -- a person who has completed one year vocational training in nursing. May be in charge of nursing in the absence of an RN. Often administer medications, perform treatments and maintain medical records required by law.

- **Nurse Aide/Assistant** -- Nurse aides supply 80-90% of the "hands-on" patient care given in nursing homes. Within four months of employment by a nursing facility, nurse aides must complete a state-approved training and competency evaluation program so that they are competent to provide nursing and nursing related services.

Physical Therapists, Occupational Therapists, and Speech Therapists, are located in a Rehabilitative Services Department**.**

- **Physical Therapist** -- (PT) – trained in restoring the function of muscles in arms, legs, backs, hands, feet, etc., through movement, exercises or treatment. Usually a consultant to the facility. Sometimes physical therapy assistants carry out the plans of the therapist.

- **Occupational Therapist** (OT) -- a person trained to conduct therapy to restore the fine muscles of the hands and arms.

Regulation of Nursing Homes

It is important for ombudsmen to understand the standards, process and agencies involved in licensing, certifying and regulating nursing homes. Nursing homes are regulated at several levels: federal, state, and local. As you will see, the federal and state levels are intricately tied together.

Federal Level: The federal government is involved in regulating nursing homes because of the payments it makes to nursing homes through the Medicare and Medicaid programs. In return for its payments, the federal government seeks to assure that participating nursing homes meet certain "minimum standards" and do not violate any of the federal anti-discrimination laws.

The top federal agency that has responsibility for regulating nursing homes is the federal Department of Health and Human Services (DHHS). Within DHHS, CMS manages the federal Medicare and Medicaid programs. CMS is responsible for administering the Medicare program. CMS and the Office of Health Planning (OHP) grant states the authority to approve or disapprove construction of new nursing homes that seek to participate in Medicare or Medicaid.

State Level: Most of the federal responsibilities have been passed on to the state. For the most part, the appropriate federal agencies simply monitor the state agencies to determine whether they are adequately performing their responsibilities. In addition, the state of Arizona has its own nursing home standards. Federal standards apply to certification requirements, while state standards apply to licensing requirements. Arizona standards follow the federal guidelines.

Local Level: The amount of local regulatory involvement in nursing homes depends on local laws. It is common, however, for the local fire marshal’s office, the sanitation department, and other local agencies to periodically review whether nursing homes are complying with local laws and regulations.

Federal Regulations and OBRA '87: Although Arizona has state laws for nursing homes, the federal government has had extensive laws for nursing homes since the 1970s because it finances resident care through the Medicare/Medicaid programs. While the state has similar laws, the federal law takes precedence over state laws and can be used by ombudsmen to resolve resident's problems.

In 1987, Congress passed a law called the Nursing Home Quality Reform Amendments of 1987, known in shorthand as OBRA '87, since it was a part of the Omnibus Budget Reconciliation Act of 1987. Among the other significant changes brought about by the 1987 amendments are:

1. The requirement for quality of care which shifts the focus of regulation to improving the quality of care for residents.
2. Focus of rules on "attaining or maintaining the highest practicable physical, mental and psychosocial well-being" instead of minimum standards.

The OBRA '87 changes have affected both state licensing and Medicare/Medicaid certification of nursing homes.

Selected Requirements for Nursing Facilities: Some of the more important federal requirements under OBRA '87 are included here.

1. **Admission:** There are a number of provisions relating to admission practices. Some of these are mentioned in other sections, like Medicaid discrimination. One federal requirement that applies to every nursing facility resident and applicant for admissions to a certified nursing facility is the Pre-Admission Screening and Annual Resident Review (PASARR).

PASARR -- Pre-Admission Screening (PAS) is a screening process for persons seeking admissions to a Medicare/Medicaid certified home. The purpose of the screening is to assure that those persons with a severe mental illness or mental retardation/developmental disabilities are not admitted to nursing homes.

Nursing facilities can only admit a seriously mentally ill person or a mentally handicapped person if s/he has been evaluated by the state and found to need nursing home care because of his/her physical and mental condition. The law requires the state to provide

other settings for individuals identified by the screen as inappropriate for nursing home care. It should be noted that the definition of mental illness does not include dementia. The Annual Resident Review (ARR) is the same type of screening for current residents of the nursing home. ALTCS is responsible for PASARR.

If a person is denied admission to or a resident is asked to leave a home because of the results of the PASARR screen, they have a right to appeal this decision. Residents who have resided in a home for 30 months as of April 1990 are entitled to remain in the home. (Is this correct?)

2. Physician Services: The health care of every resident must be provided under the supervision of a physician. The resident's attending physician must participate in preparing the written plan of care. Physicians, or physician assistants or nurse practitioners, must visit residents at least once every 30 days during the first 90 days. Thereafter, under Medicare and Medicaid, a physician must visit every 60 days. The visit may occur up to ten days after the required date. Although residents have the right to choose their own physicians, facilities must have a physician available to supervise a resident's medical care when the resident's attending physician, or one who is covering for him/her, is unavailable. This responsibility usually falls to the Medical Director, who is also responsible for the implementation of resident care policies and the coordination of medical care in the facility.

3. Nursing Services: Facilities must have sufficient nursing staff to provide nursing and related services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident, as determined by resident assessments and individual plans of care.

Facilities must provide 24-hour service by licensed nurses, including the services of a registered nurse (RN) at least eight consecutive hours per day, seven days a week. Waivers are allowed under certain circumstances. If a waiver is granted, the State Ombudsman must be notified, and the facility must notify its residents and their immediate families.

Unless a waiver has been granted, facilities must designate an RN to serve as the director of nursing on a full time basis. The director of nursing may serve as a charge nurse only

when the facility has an average daily occupancy of 60 or fewer residents.
Nursing assistants in Arizona facilities must receive a minimum of 75 hours of training and complete a competency evaluation within their first four months of employment, with a few specific exceptions. Any aide used by a facility on a temporary or part-time basis must be trained and competent. States must maintain a registry of individuals who have met the training and competency requirements.

The registry must also contain any official findings by the state of resident abuse, neglect, or misappropriation of resident property by the aide. Before using someone as a nurse aide, the facility must check with the state registry and the registry of any other state that the facility believes will have information about the aide. Arizona's state registry is maintained by the Arizona Board of Nursing.

4. Administration of Medications: Medications can be administered only by physicians, licensed nursing personnel, or by the resident if the interdisciplinary team determines that this is safe.

5. Pharmacy Services: Pharmacy services must be under the supervision of a qualified pharmacist who is responsible to the administrative staff for developing, coordinating, and supervising all pharmaceutical services. The pharmacist consultant must review the drug regimen of each patient at least monthly and report any irregularities to the Director of Nursing and/or the attending physician. These reports must be acted upon.

6. Personal Care Services: In addition to professional nursing services, facilities are required to provide necessary personal care services to all residents in a licensed health facility. Some of these personal care services include:

- Proper hydration for health;
- Dressing in clean garments;
- Bathing as frequently as necessary but at least twice weekly;
- Oral care, at least daily, including denture care;
- Hair care and grooming, including shampoo at least once a week, more often if necessary, shaving and beard trimming if desired;
- Incontinency care, including checking the resident frequently, bathing the resident as required, and changing soiled or wet bed linen or clothing

immediately;

- Changing the body position of each resident who is bedfast/chairfast in accordance with the resident's need as stated in the plan of care;
- Maintaining proper body alignment in accordance with the capabilities of each resident;
- Movement/exercise of all major joints of the body at least twice daily for each bedfast or non ambulatory resident;
- Skin care to prevent the development of pressure sores and other skin breakdown;
- Lip care to prevent dryness and cracking;
- Cleaning and cutting of the fingernails and toenails.
- Laundry services, including personal laundry;

7. Dietary Services: The food service of each facility must meet the daily nutritional needs of residents including special dietary needs. Meals must be palatable, attractive, and served at the proper temperature. The facility must provide special eating utensils (adaptive equipment) for residents who need them.

If the director or supervisor of food services is not a qualified dietitian, a qualified dietitian must be employed to consult on a frequent basis. Facilities must have sufficient personnel to provide dietary services.

8. Specialized Rehabilitative Services: Nursing facilities must either provide or arrange for specialized rehabilitative services from qualified personnel such as physical therapists, occupational therapists, audiologists and speech therapists as needed by residents to improve or maintain physical capabilities. Specialized services must be required in the resident's plan of care and provided under the written order of a physician.

9. Social Services: Medically-related social services must be provided to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident. An assessment of each resident's needs should be found in his/her record and needed services should be incorporated into the care plan. Each facility with more than 120 beds must have at least one full-time social worker, with at least a bachelor's degree in social work or similar professional qualifications, to provide or assure the provision of social services.

A facility with less than 120 beds must either have a qualified social worker as director of social services or receive consultation from a qualified social worker. In Arizona, a qualified social services director shall provide medically-related social services in accordance with the resident's assessment and care plan to maintain the highest practicable physical, mental and psychosocial well being of each resident.

10. Dental Services: Nursing facilities must provide or make arrangements for routine dental services, as covered in the state Medicaid plan for Medicaid recipients, and for emergency dental services to meet the needs of each resident. Facilities do not have to provide dental services directly or pay the cost of these services.

11. Resident Activities: Nursing facilities must provide an ongoing activities program designed to meet the individual interests and the physical, mental, and psychosocial well-being of each resident. "Activities" is an umbrella term that includes crafts, art work, social gatherings, discussion groups, outside events, and many other forms of recreational and intellectual activities. The activities program is to have a planned schedule of purposeful individual and group activities. The activities program must be under the direction of a qualified professional. According to federal regulations, an activities director must:

a. Be a qualified therapeutic recreation specialist, OR
b. Be an activities professional who is:
    - Licensed or registered, or
    - is eligible for certification as a therapeutic recreation specialist or activities professional; OR
c. Have two years experience in social or recreational programs; OR
d. Be a qualified occupational therapist or occupational therapist assistant; OR
e. Have completed a training course approved by the state.

12. Staff Training: Facilities must provide regular in-service education to ensure that nurse aides are competent to perform services. In-service education must include training for individuals providing nursing and nursing-related services to residents with cognitive impairments. Under Arizona regulations, personnel who provide direct care to residents must attend 12 hours of in-service training annually.

13. Medical Records: Facilities must maintain clinical records on all residents. For each resident the record must include identification information, the resident's comprehensive assessment, plan of care, services provided, and the results of any pre-admission screening conducted by the State and progress notes.

The facility must safeguard clinical record information against loss, destruction, or unauthorized use. Records must be kept in accordance with accepted professional standards and practice and be: complete, accurately documented, readily accessible, and systematically organized.

14. Physical Environment: Nursing facilities must care for their residents in such an environment as will promote maintenance or enhancement of the quality of life of each resident. Federal regulations contain numerous physical specifications that are too extensive to be described here. Examples of types of specifications include compliance with the Life Safety Code (fire prevention standards), emergency power, accessibility for handicapped persons, sanitation standards, minimum size of residents' rooms, and maximum numbers of residents per room. Certain specifications can be waived for buildings that were built prior to the establishment of the specifications.

Members of the Housekeeping Department staff are usually responsible for basic housekeeping chores such as sweeping and mopping floors, dusting, emptying waste cans, and cleaning furnishings. Maintenance Department staff is responsible for conducting preventative maintenance and repairs on the physical facility.

15. Disaster Preparedness: Facilities must have a written plan describing procedures to be followed in the event of a fire, explosion or other disaster. All employees must be trained in all aspects of preparedness for any disaster. This training must be on-going and include periodic drills.

16. Hospital Transfer Agreement: Each facility must have in effect a transfer agreement with one or more hospitals under which inpatient hospital care or other hospital services are available promptly to the facility's residents when needed.

17. Discharge Planning: When a facility anticipates discharge, a resident must have a discharge summary that includes:

- a summary of the resident's stay,
- a final summary of the resident's status, and
- a post-discharge plan of care that is developed with the participation of the resident and his/her family which will assist the resident in adjusting to his/her new living environment.

Discharge planning ideally begins on admission, with the resident's prognosis, expectations and prior living arrangements taken into account. As the resident progresses, or declines, discharge plans may change.

Other Services: Many other services may be provided, but are optional. Among these services are:

- Transportation services;
- Beautician and barber services; and
- Spiritual or pastoral services.
- Recreational opportunities (beyond what is included in the facility's activity program).

Residents' Council -- A formal group of residents committed to expressing the needs and desires of residents to staff. For residents, it provides a tool to exercise decision-making, an opportunity to ventilate feelings, an information forum, a vehicle for communicating to staff and a sense of group support. For the staff, it provides a means for gathering resident input, a method of clarifying roles and responsibilities within the home, help in program

policy planning, promotion of more orderly problem resolution in many instances, and greater awareness of resident problems by staff.

There is usually only one staff member present to help take notes, likely someone from Activities or Social Services, but the residents have the right to meet without any staff, if they so choose. They may also want to address key personnel face to face about an issue or problem. The facility has the responsibility to provide a space for the meeting and assist residents who require help to attend. The number and quality of services offered from this last list may be a good indication of how well a nursing home is trying to meet the needs of its residents. This is important because the average resident spends more than two years in a nursing home and has needs that go beyond food, shelter and medical supervision.

Prohibited Practices: Nursing homes have many duties and responsibilities. However, there are also certain actions and practices which facilities cannot do if they accept Medicare or Medicaid reimbursement. Examples of some of these prohibited actions and practices are:

- Facilities cannot solicit or accept payment in excess of the per diem rate paid by Medicare or Medicaid for Medicare or Medicaid recipients. However, facilities can charge for services that are provided if they are not covered by Medicare or Medicaid and they are requested by the resident.
- Facilities cannot restrict residents in the use of their personal funds.

Licensing and Certification of Nursing Homes

Licensing of Nursing Homes: A nursing home must obtain a license from the state in order to operate. When complaints come to the Ombudsman Program, the standards contained in state law tell the consumer and the ombudsman what kind of services, care, and physical surroundings to expect. If the Program needs to intervene because a home fails to meet those standards, the standards are a guide to the residents, ombudsmen and the home as to how to comply with the law.

The Survey Process: The Arizona Department of Health Services, Division of Licensing, licenses nursing care facilities annually and regulates their operation through regular monitoring. DHS makes an unannounced state licensing survey simultaneously with the federal survey every 9-15 months. They do the federal aspect of the survey under

a contract with CMS. The surveyors compare the home's operation to the standards set in the law. The surveyors are generally nurses and environmental specialists who examine resident care and the physical surroundings, respectively. Since OBRA '87, however, the survey process has focused more on the outcomes of resident care.

Some of the tasks the surveyors must perform are interviewing residents about their care, observing meal services, and observing the nursing staff pass medications to the residents. The length of the survey varies depending on the size of the home, the number of complaints being investigated in conjunction with the annual survey and the number, scope and severity of deficiencies found. While conducting the survey, DHS personnel record any violations of standards or deficiencies on a form. At the exit interview with the home's administrator, which the ombudsman can attend, the DHS surveyors summarize their findings. After the facility receives its statement of deficiencies, it must prepare a plan of correction. A time limit for corrections is set, generally 30 days, and DHS may return to resurvey for those deficiencies.

Homes must correct violations before issuance of a license. DHS can issue a conditional or a probational license while violations are being corrected. The facility's license also can be denied or revoked if the violations are substantial and it is unlikely that the situation can be corrected.

Certification of Nursing Homes: In addition to obtaining a license, most nursing homes in Arizona seek certification to participate in the federal Medicare and/or Medicaid programs. As just noted, nursing homes participating in Medicare/Medicaid are inspected every 9-15 months to determine whether they are still in compliance with the standards. CMS has a contract with the Arizona Department of Health Services (DHS) to perform inspection surveys on behalf of CMS for facilities certified for Medicare. DHS makes recommendations concerning the certification status of a facility to CMS, but CMS makes the final decision regarding Medicare certification. For Medicaid certification, however, DHS is designated the state agency responsible for both surveying facilities and determining eligibility for participation in the Medicaid program. Once a facility is in substantial compliance with the federal requirements, the facility can sign its "Provider Agreement" with the ALTCS (Arizona Long Term Care System) for our version of Medicaid and with the federal government for Medicare.

If a nursing home is violating any standards and this condition threatens the health or safety of any residents, the nursing home may be terminated--disallowed to participate--from the Medicare or Medicaid programs. Nursing homes may be terminated for less serious violations only if the violations have gone uncorrected (following a correction order by licensing officials). Nursing homes threatened with termination have the right to a hearing to challenge the decision.

Enforcement in Nursing Homes: Ombudsmen need to understand the enforcement process. Complaints registered with the Ombudsman Program often involve a violation of either the licensure or certification standards. Given that resident care and residents' rights are the most frequently recorded complaints, involvement with care standards and residents' rights is great. Ombudsmen should use the state and federal enforcement system to further the wishes of their clients.

The Arizona Department of Health Services (DHS) is the main agency responsible for enforcing the state and federal requirements. Besides the annual survey and the resurveys for deficiencies, DHS can survey based on a complaint. During a complaint survey, DHS can survey the entire facility if they feel it is necessary. These surveys and complaint investigations are a matter of public record and are available for the past five years at DHS for inspection by the public.

The annual survey, with any deficiencies and the plan of correction, is available at the facility.

If a facility cannot correct a deficiency after a survey or the facility has repeatedly violated the same requirement, the state has other enforcement mechanisms it can use including:

- Directed plan of correction
- Directed in-service training
- Denial of payment for new admissions
- Denial of payment for all individuals
- Assessing a fine
- Placing a monitor in the facility
- Appointing a receiver/temporary management for facility
- Denying, refusing or revoking a license

- Suspending a license or issuing a provisional license
- Publicly listing these actions in the home and through DHS
- Closure in emergency situations and/or transfer

The goal of the nursing home inspection system is not to close down or find fault with facilities but to assure that they operate safely. Enforcement experts believe that assessing fines for repeat offenders is the more effective enforcing mechanism or sanction. Closing a facility is the last resort since residents' lives are disrupted when they are moved and beds can be difficult to find.

"Fast Track" Decertification: Under federal law, CMS can initiate a "fast track" decertification of a Medicare skilled nursing facility if the deficiencies are "life threatening." Examples of life threatening deficiencies are: non-functioning fire alarm system or administering the wrong medication to residents and causing them harm. In a "fast track", CMS gives the facility 10 days (instead of the normal 30 days) to correct a problem or they cancel the provider agreement.

This means the federal government would stop paying for Medicare recipients in 10 days. The state then moves to revoke the license and cancels the Medicaid agreement, thus stopping both methods of payment. The purpose of the "fast track" is to get correction of serious deficiencies quickly.

When a "fast track" decertification happens, DHS notifies the Office of the State Long-term Care Ombudsman. While the ombudsman holds no regulatory role, it is the mandate of the program to protect the rights of the residents.

If a home's closure and the moving of residents is imminent, the ombudsman can (1) support or be the voice of the residents during the "fast track"; (2) assure that the residents' choices for relocation are honored; (3) assure that the residents are prepared for a disruption or move to minimize transfer trauma; and (4) assure legal representation for residents.

If a facility is closed, the ombudsman frequently serves on a committee composed of the various community and social services agencies helping in the relocation plan. The ombudsman probably will not move anyone, but will fulfill the four roles just described.

Other Agencies Involved in Regulating Nursing Homes

In addition to the agencies previously mentioned, there are a few others with responsibilities for some aspect of nursing facility life or for the welfare of residents. Some of the agencies ombudsmen are most likely to work with are described below along with their contact information.

Medicaid (AHCCCS/ALTCS) Fraud Control Unit. The Medicaid Fraud Control Unit, located in the Attorney General's Office, investigates and prosecutes fraud or abuse in the Medicaid program. This unit targets Medicaid providers: doctors, dentists, psychiatrists, hospitals, nursing homes, or any other Medicaid provider. Examples of crimes that the Medicaid Fraud Control Unit will investigate are listed.

Medicaid Fraud

- Falsification of any document related to resident care or reimbursement
- Billing for services not provided
- Providing services not ordered by physician
- Billing for higher level of services than provided
- Intentionally providing inadequate services
- Providing services for kickback
- Charging recipients for portion of covered services
- Providing adulterated or mislabeled goods

Resident Abuse and Neglect

- Striking a resident
- Verbally abusing a resident
- Intentionally providing inadequate care, in whatever way
- Improper use of physical or chemical restraint
- Requiring a resident to perform duties not part of the treatment

Theft of Resident Funds

- Stealing or misusing resident personal funds

Adult Protective Services. Adult Protective Services (APS) is part of the Division of Aging and Adult Services. It receives reports of abused, neglected or exploited, incapacitated or vulnerable adults. Upon receipt of such information, an evaluation is

made to determine if the adult is in need of protective services and what services, if any, are needed. APS assures the least restrictive form of intervention necessary. If the allegations made in the report are not substantiated, but services are needed and will be accepted by the client, appropriate referrals are made to community agencies.

APS serves individuals over the age of 18 who are:

- abused, neglected or exploited
- incapacitated to the extent that he lacks sufficient understanding or capacity to make or communicate informed decisions concerning his person, and/or:
- vulnerable: an individual who is unable to protect himself from abuse, neglect or exploitation by others because of a physical or mental impairment

Reports to APS are made through a statewide toll-free number: 1-877-767-2385

Assisted Living Facilities

What is Assisted Living?

Assisted living facilities describes a living arrangement in which a room, meals, help with activities of daily living, and protective supervision are provided to individuals who cannot live independently, but who do not need institutional care. Assisted living provides an informal, more family-like living arrangement for many older persons who, because of physical or mental impairments, can no longer live alone but can continue to live in the community fairly independently with some assistance. Many other adults with physical or mental disabilities can also live successfully in assisted living rather than in nursing homes or mental institutions.

Types of Assisted Living Facilities in Arizona

"Assisted living facility" means a residential care institution, including adult foster care, that provides or contracts to provide supervisory care services, personal care services or directed care services on a continuing basis.

"Assisted living center" or "center" means an assisted living facility that provides resident rooms or residential units to eleven or more residents.

"Adult foster care" means a residential setting which provides room and board and adult foster care services for at least one and no more than four adults who are participants in the Arizona long-term care system pursuant to Chapter 29, Article 2 of this title and in which the sponsor or the manager resides with the residents and integrates the residents who are receiving adult foster care into that person's family.

"Assisted living home" or "home" means an assisted living facility that provides resident rooms to ten or fewer residents.

Conclusion

The Long-Term Care Ombudsman Program has NO enforcement authority over facilities. Ombudsmen are to represent RESIDENTS, not to see that facilities comply with requirements. In representing residents, ombudsmen must understand the regulatory system, work with facility personnel and enforcement personnel, and advocate for the needs of residents in the system. (Note: the applicable law regarding assisted living will be included as an addendum).

MODULE IV

Equipping Long-Term Care Ombudsmen for Effective Advocacy:

A Basic Curriculum

RESIDENTS' RIGHTS

Curriculum Resource Material for Local Long-Term Care Ombudsmen

Developed by Sara S. Hunt, Consultant

National Long-Term Care

Ombudsman Resource Center

National Citizens' Coalition for Nursing Home Reform
1828 L Street, NW, Suite 801
Washington, DC 20036
Tel: (202)332-2275 Fax: (202)332-2949
E-mail: ombudcenter@nccnhr.org
Web Site: www.ltcombudsman.org

May 2005

ACKNOWLEDGMENTS
Many thanks to the Advisory Committee for the Local Long-Term Care Ombudsman Curriculum—Esther Houser, Oklahoma State Long-Term Care Ombudsman (SLTCO); John Sammons, Kentucky SLTCO; Linda Sadden, Louisiana SLTCO; Eileen Bennett, Long-Term Care Ombudsman Program (LTCOP) Specialist, Montgomery County LTCOP, Maryland; Claudia Stine, Director of Long-Term Care Ombudsman (LTCO) Services, Wisconsin LTCO; Louise Ryan, Assistant Washington SLTCO, and Sherry Culp, Nursing Home Ombudsman Agency of the Bluegrass, Lexington, Kentucky, for their review, testing, and comments. A special thanks goes to the local LTCO who field tested the draft of this curriculum module and provided feedback.

ABOUT THE AUTHOR
Sara Hunt, MSSW, is a consultant for the National Long-Term Care Ombudsman Resource Center with expertise in the areas of ombudsman training, policy development, program management, and care planning and quality of life. Sara was the State Long-Term Care Ombudsman in Louisiana for five years (1981-1986) and has served as a consultant to the Ombudsman Resource Center since 1987. For more than twenty-five years Sara has been developing and conducting training programs, most of those for ombudsmen. She is co-author of Nursing Home: Getting Good Care There.

ABOUT THE PAPER
This curriculum module was supported, in part, by a grant, No. 90AM2690, from the Administration on Aging, Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

Module IV: Resident Rights

OUTLINE

INTRODUCTION

As an ombudsman, you not only have an obligation to provide information about residents' rights, but also a further obligation to assist residents in exercising those rights.

This module provides an understanding of residents' rights and the role of Long-Term Care Ombudsman (LTCO) in supporting residents in exercising their rights. It provides a way of thinking about residents' rights and an approach for ombudsman work regardless of the specific issue. Topics covered include:

- empowerment as a basic LTCO approach,
- the principles underlying residents' rights,
- specific residents' rights provisions,
- how residents can be encouraged and supported in exercising their rights, and
- the role of LTCO.

The appendices contain a variety of resources. Appendix A has the federal residents' rights provisions for nursing facilities. Specific resources on resident assessment and care planning and on freedom from restraints are in the Appendices B and C. A list of resources on residents' rights topics for further information and for use in training is in Appendix D. An excellent resource for more specific information on many of the federal residents' rights provisions is An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87. A revised version is due in 2005 from the National Long-Term Care Ombudsman Resource Center at the National Citizens' Coalition of Nursing Home Reform.

NOTE: While the ombudsman process and approach is very much the same regardless of where a resident lives, the tools that are available in terms of law and regulation are not. Much of this module references federal law and regulation, but it is important to note that these laws and regulations are applicable only to nursing facilities that accept Medicaid or Medicare. There is no comparable federal law or regulation for adult residential care settings, such as assisted living facilities. You must rely solely on state law and regulation for adult residential care settings and for nursing homes that do not accept Medicaid or Medicare.

EMPOWERMENT

What It Is

"Empowerment means to give power to another or to take it for oneself. The dictionary definition is 'to give authority to, to authorize.' This concept includes an advocate's conscious decision to enable a disadvantaged person or group to become capable of self-advocacy." [1]

As an ombudsman, empowerment needs to be your primary way of relating to individuals. Empowerment is the foundation of your work. You are always seeking to enable others to speak up on their own behalf and to have direct, responsive communication with other residents, family members, and staff. This section discusses dimensions of empowerment and your role in empowering others.

The Need for Empowerment[2]

All of us have our own way of expressing ourselves, of participating in a community of people, and of dealing with the problems of everyday life. These are all situations in which we develop our own way of living in the world. How we go about this depends a lot on how we perceive and exercise our power in a given situation. When we feel at a disadvantage, we may approach matters with that disadvantage in mind.

1 Excerpt from training manual, The Advocacy Spectrum, July 1979, Washington, DC: National Public Law Training Center.

2 The sections on empowerment, resident councils, and family councils, were developed by former LTCO, Cathie Brady, Connecticut, and Barbara Frank, Massachusetts.

In long-term care, there are many factors that affect each resident's own sense of

empowerment. Personal factors include his or her individual history or life experience, current health, and current support system. The facility's size, culture, and physical environment also have an impact. For example, the size and shared living areas of a smaller, assisted living home may make standing up for oneself more difficult. The inter-personal dynamics are also more deeply rooted in a smaller place.

The experience of living in a facility can considerably dampen an individual's sense of self and of his/her capabilities. It often engenders a sense of powerlessness in people. Long-term care facility residents find themselves thrust into a new environment with new rules and new social codes. One researcher found that residents of one long-term care facility thought they were not supposed to talk because they did not see any other residents talking with each other.[3]

Residents often do not know how things work in the facility. The very experience of living in an institutional setting can "dis-empower" residents. They don't want to upset their caregivers and may not have the energy, health, or mobility to figure out how to get help. Regular conversations and interactions with people residents know, interactions that strengthen their sense of self, might not continue. These losses can contribute to a sense of powerlessness, disorientation, and despair.

It is important to remember that generational, gender and ethnic differences can affect a resident's sense of empowerment. Most of today's nursing home and assisted living facility residents are women over the age of seventy. They may have a different approach to making things work than men or younger individuals. Traditionally, they have either depended on others to speak up for them or have accepted the status quo.

3 Kaakinen, JR. Living With Silence. The Gerontologist. 1992. Apr; 32(2):258-64.

The Role of the Ombudsman

Ombudsmen can play an important role in helping people restore their own sense of themselves and regain their sense of personal power and voice. Residents who have always felt it easy to speak up may merely need to be pointed in the right direction and be given a little assurance that they are within their rights. Others may need a lot more encouragement; they may need you to go for them or with them. If people are sick, weak, immobile, or alone, you may have to carry more of the load for them; they may have limits on what they want to take on for themselves. They may want to address their problems but will need you to work with their condition.

The first step in this process of empowering residents is simply to have genuine meaningful connection with residents, to get to know them as individuals. Real human connection can be immensely restorative. In the course of that connection, residents may share concerns about their day-to-day experience. How ombudsmen respond and work with these concerns can go a long way in "empowering" residents and restoring their sense of self. It is important throughout such a process to relate honestly and authentically to the resident and to the situation.

Resident Directed

It is also important to take the resident's experience and viewpoint very seriously and proceed at a pace and in a direction in which the resident is comfortable. You must temper your urge to make things better. If you rush to problem solve and take over, it can be just as disempowering as the rest of the resident's experience. If you take your lead from the resident and see yourself as the carrier of the resident's message, you can help the resident regain control of his or her life.

By establishing meaningful relationships with residents, taking their experiences and concerns seriously, and creating avenues for communication with staff who can resolve problems, you are able to address problems at the earliest stages before they become major complaints. If residents feel they can tell their problems to staff and have those problems addressed, they are truly empowered.

Getting to know residents, their living dynamics, and establishing rapport are essential in learning how to go about whatever problem solving is needed, in a way that works for residents. The goal is to foster an environment in which residents, families and staff can talk with each other and make life work well for those living and working in the facility. Generational, gender, and ethnic differences can affect a resident's sense of empowerment.

Setting

Be aware of the setting and how it impacts your role in empowering residents. In a smaller assisted living facility for example, you are walking into a living room. Everyone sees you. Everyone knows the purpose of your visit. Smaller spaces magnify everything; therefore, a small intervention can have a big impact. Larger settings may have layers to move through to find out how a problem can be resolved. It may require a more formal approach to bringing the problem to the people with authority to address it.

Problem Solving by Empowerment

When ombudsmen are able to engage in a problem-resolution process with one resident, everyone learns more about addressing issues. The resident can feel more comfortable and confident about bringing up concerns in the future. Facility staff can feel more comfortable about being open to what residents have to say. As an ombudsman, you can build on the rapport you have established and use it for the next problem-solving situation. Working out a channel for solving problems can open the door for future communication between the resident and the staff, once they have learned how to do it.

Some facilities may be more open to hearing and addressing residents' concerns. Others may be more resistant or defensive. In bringing problems forward, you are teaching everyone how to work them out. Often the facility staff is more comfortable making all the decisions. They have to learn how to listen better to residents and how to be responsive to residents' needs.

There are times when your presence as an ombudsman can help "level the field" and add balance for residents. Sometimes just being in a facilitated dialogue between residents and staff helps solve the problem. When this happens, you have just assisted in starting an empowerment process. Each time a resident is successful, he/she feels stronger and is

more likely to bring forward concerns in the future.

Assisting residents in the process of becoming empowered is hard work. Ombudsmen must remember that at the end of a visit, you return to your home, but the resident stays in his/her home. Change can at times be so slow that you get frustrated; however, you can go no faster in facilitating change than the comfort level of the resident or residents.

Remember that you can go no faster in facilitating change than the comfort level of the resident or residents.

Proceed in a way that is respectful of inter-personal dynamics and gradually find an approach that is comfortable for residents.

4 The full title of this document is the State Operations Manual, Appendix PP, Guidance to Surveyors for Long Term Care Facilities, Rev. 5, 11-19-04. The section that covers the survey protocols is, Appendix P, Survey Protocol for Long Term Care Facilities, Rev. 1, 05-21-04. In this resource document, the survey protocols are referred to as the State Operations Manual.

NURSING HOME RESIDENTS' RIGHTS UNDER THE NURSING HOME REFORM LAW

Introduction

Certain rights are set forth in the United States Constitution for all citizens. Individuals who live in long-term care facilities do not lose these rights when they enter a congregate living environment. In fact, they are guaranteed additional rights under state and federal laws specific to their status as residents! These rights are provided for primarily in the following sources:

• Federal Nursing Home Reform Law: The Omnibus Budget Reconciliation Act of 1987 (OBRA '87), as amended, Medicaid Provisions (§1396r), and Medicare Provisions (§1395i-3)

• Federal regulation: Medicare and Medicaid Requirements for Long Term Care Facilities, September 26, 1991, 42 U.S. Code of Federal Regulations, (§483).

• State laws

For your information, the residents' rights excerpts from the Medicaid provision of the federal law are included in Appendix A. While many of the rights guaranteed by each of these sources are very similar, it is important that you be familiar with all of them.

A very useful resource for understanding residents' rights is the Guidance to Surveyors for Long Term Care Facilities. These guidelines are part of the Centers for Medicare & Medicaid Services (CMS) State Operations Manual 4, the document that surveyors use to determine whether a facility has met the federal requirements. Another useful resource is An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87 by the National Long-Term Care Ombudsman Resource Center.

Key Provisions

There are two key provisions in the federal law (Nursing Home Reform Amendments[5] of the Omnibus Budget Reconciliation Act of 1987 or OBRA '87) that establish the foundation for all the other provisions: Quality of Care and Quality of Life.

- Quality of Care says a nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care.

Resources:

- Guidance to Surveyors
- LTCO Guide to OBRA '87

- Quality of Life says a nursing facility must care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.

There is the same underlying theme in each of these provisions: facilities must be responsive to the particular preferences and needs of each individual resident. Building on that premise, the residents' rights provisions follow the Quality of Life section in the law. Residents' rights are like the directions for achieving quality of life. If facilities follow these directions and fully implement residents' rights, they will be promoting quality of life for each resident.

5 The Nursing Home Reform Amendments is also referred to as the Nursing Home Reform Law or as OBRA '87.

Residents' rights also have implications for quality of care requirements. Since residents' rights and quality of life are related, what factors do residents consider important for quality? In 1985, the National Citizens' Coalition for Nursing Home Reform asked 450 residents in 15 cities across the country what quality meant to them. Studies since then continue to support the importance of these same factors to residents.[6] A few central issues were poignantly and consistently identified. Many of these were incorporated as provisions in the Nursing Home Reform Law. They include the following:

- Kind treatment by staff,
- Respect for residents' dignity and being treated as adults,
- Opportunities for choice and input in care and services, particularly related to food, activities, and personal schedules,
- Privacy.

Basic Themes

The residents' rights listed in the federal law, and therefore all of the regulations that follow from them, embody four basic themes. If you learn and remember these four themes, you will understand how to work on the specific rights. You soon will learn many of the specific residents' rights because you will be looking up the exact language of the provisions that apply to an issue you are asked to resolve. The role of the ombudsman is to help residents, their families, and facility personnel understand what these themes mean and how they can be achieved.

The four themes are:

1. Communication
2. Choice
3. Decision-making
4. Participation

6 Kane, R. Good (or Better) Quality of Life for Nursing Home Residents: Roles for Social Workers & Social Work Programs. Presentation for Evaluating Social Work Services in Nursing Homes: Toward Quality Psychosocial Care and its Measurement, Institute for the Advancement of Social Work Research, Washington, DC. December 2-3, 2004.

The following examples illustrate how these four themes encompass residents' rights.

Communication

Effective, on-going communication between residents and staff is essential to fulfilling residents' rights. A resident may say, "I don't want this food." What does this mean? It could mean that the resident is refusing a special diet, or it could be the resident's way of saying that the food is unpalatable because it is cold, bland, or is food that the resident has never liked. There may be a different, unrelated problem behind the refusal of the food. When residents exercise their right to say, "No," staff need to ask questions and observe until they fully understand what the resident is really expressing. Even residents who are not very articulate or who have some degree of memory impairment can express choices.

Specific examples of rights pertinent to communication include residents' rights to:

- be fully informed of his or her rights and all rules and regulations governing resident conduct and responsibilities, orally and in writing, in a language the resident understands;
- participate in planning his or her care and treatment; and
- voice grievances without discrimination or reprisal AND have prompt efforts by the facility to resolve these.

Choice

Each resident has the right to exercise choice and have those choices respected. The introduction to residents' rights in the federal regulations says, the resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility. A primary example is the right to reside and receive services with reasonable accommodation of individual needs and preferences. From the resident's perspective, this right means that the facility and staff must allow each resident to direct the patterns of his/her daily life, as well as treatment methods and goals.

From the staff's perspective, resident choice means that the staff needs to think creatively, to see life from the resident's viewpoint when a request is made or a preference is stated. Instead of saying, "No," or, "We can't do that because. . .," the staff should say, "Let's see what we can do." Staff and residents can brainstorm together and then take action. Exercising choice means considering ways to accommodate residents' preferences and decisions. Staff have a responsibility to help residents exercise their rights, even when staff feel that helping is not their duty. Examples are staff helping a resident to smoke or not interfering when a resident visits with persons whom the staff feel are not appropriate choices of friends. The law challenges the facility to focus on meeting the needs and desires of each individual resident, not on maintaining the customary routines of the institution.

There are some other important dimensions of exercising choice. Making a choice is not a time-limited event. If a resident says she does not care what clothing she wears that day, the person's choice does not mean that she will never have a clothing preference. An individual's choice and preferences may change. After a person has been in the facility awhile, or if her condition changes, she may make different choices than the ones previously stated. Exercising choice is a continual process.

Decision Making

Each resident has the ability to exercise his/her own rights unless that individual has been adjudicated incompetent according to state law. To exercise decision-making, residents need full information to be able to make a truly informed decision. They need accurate information about alternatives and the consequences, short- and long- term, of the decisions they are considering. Decision making is the implementation of exercising choice.

Another aspect of resident decision making is being in an environment that is truly encouraging and supportive. Residents need to feel free to make their own decisions without fearing that they will be declared incompetent or discharged if their decisions differ from what professionals recommend or from what their family wants. Once a decision is made, residents need to know that their choice will be respected. One of the requirements of the Nursing Home Reform Law is that nursing homes must protect and promote the rights of each resident.

A few specific examples of rights in this area are a resident's right to:

- manage his or her financial affairs;
- work or not work; and
- choose a personal attending physician.

Participation

Residents are to participate in planning their care and treatment and to participate in:

- resident groups if they so choose;
- social, religious, and community activities;
- the survey process; and
- the administration of the facility.

Even residents with a diagnosis of dementia can participate in planning care and exercising choice. If a resident's preference cannot be honored, the staff needs to engage in problem solving with him/her to find a solution that is as close as possible to what the resident wants. Residents need to be familiar with the grievance process in the facility and have confidence that the process will work. Facilities are required to assure resident and advocate participation in the administration of the home.

Honoring, upholding, residents' rights is a process; it is not something that is done once, checked off a list, and forgotten because it is a standard that has been met.

These four themes—communication, choice, decision making, and participation— embody the approach, attitude, and philosophy of implementing residents' rights. They have to be continuously exhibited. As an ombudsman, you may be the facility's best model and teacher for implementing residents' rights.

SUMMARY LISTING OF RIGHTS

The following is a summary listing of the provisions of residents' rights for individuals living in nursing facilities certified for Medicare or Medicaid. Although they are often mirrored in state law, the rights presented here are based on federal law and regulation. Their purpose is to safeguard and promote dignity, choice, and self-determination of residents. The citations refer to the federal Requirements for Long-Term Care Facilities.

As with all specific provisions of the law or regulations, it is always advisable to verify any information you rely on in developing or presenting a case by checking the source document.

Rights Regarding Health Care

- To be free of physical restraints not documented as medically necessary [§483.13]
- To have his/her choice of physician [§483.10 (d)]
- To be transferred or discharged only after reasonable notice is given; and only for medical reasons, the safety or welfare of other residents, or for non-payment [§483.12]
- To be protected from transfer or discharge from a Medicaid or Medicare certified facility solely because the resident becomes eligible for Medicaid or Medicare payment [§483.12 (d)]

Right to Exercise Individual Liberties

- To exercise his/her rights as a resident and a citizen [§483.10 (a)]
- To complain and make suggestions without fear of retaliation [§483.10 (f)]
- To a dignified existence and self-determination [§483.10]
- To be free of verbal, sexual, physical, and mental abuse [§483.13 (b)]
- To participate in social, religious, and community activities [§483.15 (f)]
- To have his/her and use own clothing and possessions, including some furnishings [§483.10 (l), §483.15 (h)(1)]
- To manage his/her personal affairs, or if this is delegated to the facility, to receive an accounting report every three months and on request [§483.10 (c)]
- To have access for visits with family, friends, and representatives of certain agencies, including the ombudsman [§483.10 (j)]
- To share a room with his/her spouse, if he/she is a resident of the same nursing home and they both consent [§483.10 (m)]

Rights to Information

- To be informed of his/her rights, the rules and regulations of the nursing home [§483.10 b)]
- To receive prompt efforts to resolve grievances [§483.10 (f)]
- To have any significant change in his/her health status reported to him/her

[§483.10 (b)(10)(B)]

- To be informed of his/her condition and planned medical treatment, and to participate in planning or refusing that treatment [§483.10 (b)(3) and (4)(d)(3)]
- To examine the results of the most recent survey conducted by state or federal surveyors of the facility [§483.10 (g)]
- To be informed of the bed reservation policy for hospitalization [§483.10 (b)(2)]
- To be told of all services available and all costs, including charges covered or not covered by Medicare, Medicaid or the basic per diem rate [§483.10 (b)(6)]

Rights to Privacy

- To personal privacy in medical treatment and personal care [§483.10 (e)(1)]
- To send and receive unopened mail [§483.10 (i)]
- To receive visitors in privacy [§483.10 (e)(1)]
- To have his/her personal and medical records treated confidentially [§483.10 (e)]
- To have reasonable access to use of a telephone where calls can be made without being overheard [§483.10 (k)]

Rights for Families or Legal Representatives [7]

- To be notified within 24 hours of an accident resulting in injury, a significant change in the resident's physical, mental, or psychosocial status, a need to alter treatment significantly, or a decision to transfer the resident [§483.10 (11)]
- To be notified of appeal rights [§483.12 (a) (6) (iv)]
- To be notified promptly if change in room or roommate or in resident's rights provisions [§483.10 (b) (11) (i) (D) (ii) (A) and (B)]
- To be notified if the facility receives a waiver of licensed nurse staffing requirements [§483.30 (c) (7), (d) (1) (B) (v)]
- To participate in the care planning process [§483.20 (d) (2) (ii)]
- To have immediate access to the resident, subject to the resident's rights to deny/withdraw consent at any time [§483.10 (j) (1) (vii)]
- To participate in a family council which may meet privately in space provided by the facility and receive the facility's cooperation in its activities [§483.15 (c) (2)]
- To make recommendations to the facility, and the facility is required to "listen to the views and act upon grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility." [§483.15 (c) (6)]

7 An Ombudsman's Guide to the Nursing Home Reform Amendments Of OBRA '87. revised by S. G. Burger, National Long-Term Care Ombudsman Resource Center, National Citizens' Coalition for Nursing Home Reform. 2005.

Rights Regarding Incompetent Residents

When an individual is judged by a court to be incompetent in accordance with state law, the resident's rights "shall devolve upon, and, to the extent judged necessary by a court of competent jurisdiction, be exercised by the person appointed under state law to act on the resident's behalf." [§483.10 (3)]

8 Much of this section is from: B. Frank, An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87, The National Center for State Long-Term Care Resources, National Citizens' Coalition for Nursing Home Reform, February 1992.

DISCUSSION OF SELECTED RIGHTS

This section contains a detailed discussion of some of the residents' rights that are frequently problematic. In some instances, the discussion includes tips for ombudsman practice. Be sure to check the exact language of the applicable law before providing specific information or pursuing complaints. The citations refer to the federal Requirements for Long-Term Care Facilities.

Privacy

Private Telephone Conversations [§483.10 (k)]

Private telephone conversations are included in the federal law. Residents may face a number of problems using the telephone in a facility. The law and the Guidance to Surveyors say that residents must have reasonable access to the use of a telephone where calls can be made without being overheard. That includes placing telephones at a height accessible to residents in wheelchairs and adapting telephones for use by the hearing impaired.

Privacy [§483.10 (e), §483.15 (c)]

Privacy also includes the rights to privacy with whomever the resident wishes to be private. Private space may be created in a number of ways; it must be accomplished in a way that does not infringe upon the rights of other residents. Privacy extends to medical treatments and bathing. It also includes visual privacy and for visits or other activities, auditory privacy to the extent desired.

Self-Determination

There are several rights that underscore the self-determination and individuality principles that are so clearly stated in the Nursing Home Reform Law's Quality of Care and Quality of Life provisions. A few of these rights are listed here because they counter the institutional approach that often exists. These rights require the facility to adapt to each resident's routines and preferences instead of expecting the resident to adjust to the facility's schedule.

• Residents can choose activities, schedules, and health care consistent with their interests, assessments, and plans of care. Staff is required to make adjustments to allow residents to exercise choice. [§483.10 (b)(3) and (4), §483.15 (b)]

• Residents are to reside and receive services with reasonable accommodations by the facility of individual needs and preferences. [§483.15 (e)] The Guidance to Surveyors says the facility's physical environment and staff behaviors are to assist residents in maintaining and/or achieving independent functioning, dignity, and well-being. Facilities are directed to adapt such things as schedules, call systems, and room arrangements to accommodate the resident's preferences, desires, and unique needs. Facilities must learn each resident's preferences and take them into account when discussing changes of room or roommates and the timing of such change.

Facilities must adapt to each resident's routines and preferences instead of expecting the resident to adjust to the facility's schedule.

TIPS FOR OMBUDSMAN PRACTICE

- You may need to help staff, residents, and their families understand what these rights mean in everyday life. You can do this by modeling, observing, and asking questions.

- Be willing to assist staff and residents in listening to each other and working out solutions that are acceptable to both.

- Be alert for opportunities to suggest that residents can exercise choice and have their choices respected.

- Help staff think in terms of “How can we. . .” instead of “We can't do that because…”

- Help staff and residents brainstorm about a range of ways to accommodate individual needs and preferences.

- Encourage residents to express their preferences. When residents are unable to do this, encourage family members to tell staff about the resident's preferences and routines.

- Share ideas and/or approaches that have worked in other facilities.

- Use care planning as a problem-solving vehicle to focus everyone’s attention on the resident’s needs, routines, and preferences. Advocate for care plans that build on the resident's schedules and strengths.

Participation in Planning and Treatment

Right to Be Informed [§483.10 (b)(3),(4), and (11)]

Residents are to be fully informed in advance about care and treatment and of any changes in care or treatment that may affect the resident's well-being. This means that a resident receives the information necessary to make a health care decision.

To determine whether this right is being upheld, surveyors might ask residents questions like:

- How are you involved in planning your care?
- If your care plan is changed, how do you find out about it?
- Does staff explain how these changes will affect you?

These three questions might also be appropriate for you to routinely ask residents when helping them identify strategies for good care.

Residents are to participate in planning and making any changes in their care and treatment. [§483.10 (d)(3)] According to the Guidance to Surveyors, this means that the resident has an opportunity to select from alternative treatments. Even if a resident's ability to make decisions about care and treatment is impaired or if the resident has been adjudicated incompetent, the resident should be kept informed and be consulted on personal preferences.

The comprehensive care plan is to include measurable objectives and timetables to meet a resident's medical, nursing, mental, and psychosocial needs that are identified in the comprehensive assessment. [§483.20(d)(1)]

In practice, many residents and family members do not play an active role in the care planning process. Often the conference is short and pre-emptive; selected staff report on the resident and their anticipated treatment objectives. Staff members are usually too busy to really involve the resident (and/or family) in advance to work together toward goals and choices. Yet the resident has the right to "choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care," and to "make choices about aspects of his or her life in the facility that are significant to the resident." [§483.15(b)] The assessment and care planning process are often the keys to good care and, typically, are areas where improvement is needed.

In order to fully participate in planning care and treatment, residents may need information and support. Ombudsmen can be helpful to residents and their families in a number of ways.[9]

- Encourage residents to attend their care-planning meeting.
- Help them prepare by identifying their needs and goals as well as potential strategies and options. If necessary, help them get the information they need before the meeting such as their current care plan or medication orders.
- Let them know that a family member or you may be present during the meeting, and that they can request a care-planning time that allows the family to attend.
- Advocate for care planning to be conducive to resident participation.
- Ask questions if professional jargon is used instead of language that everyone understands.
- Be sure the resident's voice is solicited, heard, and respected.
- If necessary, direct the staff to talk with the resident instead of speaking about the resident in the third person as if the resident were not present.
- Ask for options, alternatives, and/or more information if there are differences that need to be resolved.
- Ask whether the resident understands and agrees with the care plan.

Be sure the care plan is specific enough to know if it is being followed and who is responsible for implementing each section.

9 More information can be found in: S. Hunt and S. Burger, Using Resident Assessment and Care Planning As Advocacy Tools: A Guide for Ombudsmen and Other Advocates, National Citizens' Coalition for Nursing Home Reform, July 1992, updated November 1995.

Freedom from Restraints

"While restraints are rarely the best care option available, they are often the most familiar method to resolve situations such as 'wandering,' 'falling,' and 'behavior problems.' Facilities commonly use restraints, presuming they ensure safety, in fear of litigation should a resident fall."[10]

Residents are injured by improperly applied and infrequently checked restraints or injure themselves attempting to get free of them. In the worst case, physical restraints result in death when a resident becomes entangled in the restraint. Restraints are the most obvious substitute for sufficient numbers of staff, but staff shortages make it more difficult to monitor restraints. Moreover, poor training of staff leaves them unable to apply restraints properly and/or recognize signs that harm is being done.

Although restraints can be "enablers," they are more often used to restrict movement. A chart on the impact of physical and chemical restraints and alternatives can be found in Appendix C at the end of this chapter.

The Nursing Home Reform Law provides protections from restraints:

- Freedom from restraints is "the right to be free from physical or mental abuse, corporal punishment, involuntary seclusion, and any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms. [§483.13 (a)(b)]

Restraints may only be imposed:

- To ensure the physical safety of the resident or other residents; and
- Only upon the written order of a physician that specifies the duration and circumstances under which the restraints are to be used (except in emergency circumstances specified by the Secretary [HHS]) until such an order could reasonably be obtained."

[10] S.G. Burger, Inappropriate Use of Chemical and Physical Restraints, Washington, DC: The National Center for State Long-Term Care Ombudsman Resources, National Citizens' Coalition for Nursing Home Reform, 1989, pp. 3-4.

Restraints are defined in the following way in the Guidance to Surveyors:

> • "Chemical restraint" means a psychopharmacologic drug that is used for discipline or convenience and not required to treat medical symptoms. Psychopharmacologic drugs may be administered only:
>
> - On the orders of a physician, and
> - As part of a plan designed to eliminate or modify the symptoms for which the drugs are prescribed, and
> - If, at least annually, an independent, external consultant reviews the appropriateness of the drug plan of each resident receiving such drugs.
> - Physical restraints include, but are not limited to, leg restraints, arm restraints, hand mitts, soft ties or vests, and lap cushions and lap trays the resident cannot remove. Also included as restraints are facility practices which meet the definition of a restraint, such as tucking in a sheet so tightly that a bed-bound resident cannot move, bedrails, or chairs that prevent rising, or placing a wheelchair-bound resident so close to a wall that the wall prevents the resident from rising."[11]

11 Guidance to Surveyors (The Interpretive Guidelines) for Long-Term Care Facilities, State Operations Manual. Centers for Medicare & Medicaid Services. Baltimore, Maryland. Section revision 06-95, PP-45.

The Guidance to Surveyors discusses the use of restraints in depth. Some key provisions from that document regarding using restraints in nursing homes follow.

• If the restraint is used to enable the resident to attain or maintain his or her highest practicable level of functioning, a facility must have evidence of consultation with appropriate health professionals, such as occupational or physical therapists. This consultation should consider the use of less restrictive therapeutic intervention prior to using restraints as defined in this guideline for such purposes.

• If a resident chooses to include a restraint as part of care and treatment, the device may be used for specific periods for which it has been determined to be a therapeutic intervention (e.g. a bedrail used by a resident for turning).

- For a resident to make an informed choice about the use of a restraint, the facility should explain to the resident the potential negative outcomes of restraint use.
- The resident's right to refuse treatment includes the right to refuse restraints.

• Restraints may NOT be used to permit staff to administer treatment to which the resident has not consented.

• If the resident needs emergency care, restraints may be used for brief periods to permit medical treatment to proceed unless the facility has noticed that the resident has previously made a valid refusal of the treatment in question.

• The decision to apply physical restraints should be based on:
- The assessment of each resident's capabilities.
- An evaluation of less restrictive alternatives and the ruling out of their use.
- The plan of care should contain a plan of rehabilitative training to enable the progressive removal of restraints or the progressive use of less-restrictive means.

• Guidelines are established for checking and releasing residents from restraints. Federal guidelines require that residents in restraints be checked and released from restraints every two hours.

• The use of restraints is to be documented in the resident's clinical record on each tour of duty during which the restraints are in use.

Progressive nursing homes have been able to drastically reduce the use of restraints through alternative care programs. For information about restraints, ways to reduce or eliminate restraints, and reports from nursing homes about their restraint-reduction successes, consult the following resources.

"Untie the Elderly" (www.ute.kendal.org). Read their newsletter, and access the steps toward a successful restraint-reduction program prepared by the Pennsylvania Restraint Reduction Training Team.

- Nursing Home Compare (www.medicare.gov). From this site, access facility specific information regarding the use of physical restraints by facility. The information is based on the Minimum Data Set information submitted by the facility.

- Additional resources are listed in Tips for Ombudsmen section that follows.

TIPS FOR OMBUDSMAN PRACTICE

If there is evidence of a problem with the use of physical or chemical restraints, consider the following actions. Be sure to follow ombudsman policies regarding complaint handling and encourage the complainant to engage in self-advocacy.

- Determine how the decision to use the restraint was made.
- Was the decision an informed decision made by the resident or by the individual with the legal authority to authorize medical treatment for the resident?
- Does the resident understand the potential detrimental effects of the restraint?
- Were other options presented?
- Does the facility know what the resident wants or needs?
- Is the restraint being used to treat a symptom instead of the root cause of the symptom?

Consider using the following resources in your review and preparation for resolution in addition to federal and state laws and regulations:

The Guidance to Surveyors regarding restraints and pertinent care issues. Resident Assessment Protocols (RAPs) of the Resident Assessment Instrument on physical restraints, psychotropic drug use, and others that might be relevant.

The chart in Appendix C, “Context For Freedom From Physical Or Chemical Restraints Used For Discipline or Convenience.”
Good Care is Restraint Free,” Nursing Homes: Getting Good Care There. Burger, SG. Fraser, V. Hunt, S. and Frank, B. Impact Publisher, 1996, revised 1999. Also available from the National Citizens’ Coalition for Nursing Home Reform, 1828 L Street, NW, Suite 801, Washington, DC 20036. (202)-332-2275; www.nursinghomeaction.org

Ask for a care plan review to:
- Determine the reason the restraint is being used.
- Determine what alternatives have been tried
- Consider other approaches to meeting the resident's need.

Protection Related to Transfer/Discharge

Residents come to view the nursing home and even their room in the facility as their own home. Moving out of the facility can be traumatic for the resident. In one landmark case, a New York State court ruled that a resident should not be made to go because the damage to her health would be greater if she were moved against her will than it would be if she remained in the facility with a lower level of service.

To minimize transfer trauma, residents need to be involved in decisions surrounding the relocation and be given time to adapt to the change. Studies of transfer have identified important steps that can be taken to mitigate the negative impact of relocation. The steps include:

Reasons for Transfer/Discharge from a Facility

The Nursing Home Reform Law and federal regulations specify permissible reasons for transfer and establish protections such as advance notice, the right to appeal a transfer, and the right to return to the nursing home if appropriate. [§483.12] Some of these protections are outlined below.

Nursing homes must not transfer or discharge a resident unless the:

- facility is unable to meet the resident's medical needs;
- resident's health has improved such that he/she no longer needs nursing home care;
- safety of other individuals is endangered;
- health of other individuals would be endangered;
- resident has failed, after reasonable notice, to pay for his/her stay in the facility; or
- the facility ceases to operate.

A resident's refusal of treatment is not a reason for transfer unless the facility is unable to meet the needs of the resident or protect the health and safety of others.[12]

[12] Guidance to Surveyors, State Operations Manual. Centers for Medicare & Medicaid Services, Baltimore MD, 06-95. PP.32-40.

Notice to Residents and Their Representatives before Transfer/Discharge from a Facility

Timing

The notice must be given at least 30 days in advance with these exceptions:

- The health or safety of individuals in the facility would be endangered;
- The resident's health has improved such that he/she no longer needs nursing home care;
- An immediate transfer/discharge is required by the resident's urgent medical needs or
- A resident has not resided in the facility for 30 days.

Content

The notice of discharge or transfer must include:

- the reasons for transfer;
- the effective date of transfer;
- the location to which the resident is to be transferred or discharged;
- the resident's right to appeal the transfer;
- the name and address of the State Long-Term Care Ombudsman and
- the address and telephone number of Protection and Advocacy Services if the resident has a mental illness or a developmental disability.

Individuals Who Receive Notice

The notice must go to:

- the resident;
- a family member if known;
- the resident's legal representative and legal guardian, if known; and
- the regional office of the division of mental health for residents who are developmentally disabled.

In some states, notice must be given to the State or Local Long-Term Care Ombudsman.

Orientation before Transfer/Discharge from a Facility [§483.12 (7)]

A facility must prepare and orient residents to ensure a safe and orderly transfer from the facility. The Guidance to Surveyors states that:

"Sufficient preparation" means the facility informs the resident where he or she is going and takes steps under its control to assure safe transportation. The facility should actively involve, to the extent possible, the resident and the resident's family in selecting the new residence. Some examples of orientation may include trial visits, if possible, by the resident to a new location; working with family to ask their assistance in assuring the resident that valued possessions are not left behind or lost; orienting staff in the receiving facility to resident's daily patterns; and reviewing with staff routines for handling transfers and discharges in a manner that minimizes unnecessary and avoidable anxiety or depression and recognizes characteristic resident reactions identified by the resident assessment and care plan.

Refusal of Certain Transfers [§483.10 (o)]

Transfer to a portion of the facility (a distinct part) with a separate certification under Medicare or Medicaid is considered transfer to another facility and entitles a resident to all the protections (notice and appeal rights) of such a transfer.

Residents have the right to refuse a transfer to another room within the facility if the purpose of the transfer is to relocate the resident from a part of the facility that is a skilled nursing facility to a part to the facility that is not skilled, or vice versa. However, there may be financial consequences attached to the decision.

Good Provider Practice Before Deciding to Transfer or Discharge

Often the basis for a transfer or discharge can be eliminated by close attention to medical problems, changes in the environment, or alterations in the staff interventions. If the transfer or discharge is due to a significant change in the resident's condition, "then prior to any action, the facility must conduct the appropriate assessment unless the change is an emergency requiring an immediate transfer." Guidance to Surveyors at F-201, F-287.

TIPS FOR OMBUDSMAN PRACTICE

When issues arise regarding transfer or discharge from a facility, consult federal and state laws and regulations for their exact requirements. The Guidance to Surveyors describes in more detail factors facilities must consider in making the decision to transfer a resident. It also discusses a facility's obligations to meet the needs of residents according to the quality of care and quality of life requirements. Although there can be great variation in cases, there are some general actions you might consider on behalf of a resident.

- Examine the notice to ensure that it complies with all of the requirements. If it does not comply with all of the requirements, it is not a valid discharge notice and the 30-day time period has not started.
- Focus on the stated reason for transfer/discharge and begin problem resolution.
    - What is the real problem or issue?
    - What approaches has the facility tried to resolve the problem?
    - Has the facility used outside resources when appropriate?
    - What is the resident's role in resolving the problem?
    - Is this an issue where a care-planning conference might be useful?
- Contact the SLTCO if the resident wishes to file an appeal or if the resident is unable to file an appeal.

Notice Before Change in Room or Roommate

Transfer from one room to another can be traumatic. In 1990, the Nursing Home Reform Law was amended to give residents the right to refuse to be transferred from a Medicare/Medicaid bed to a Medicaid only bed. This amendment was adopted in order to address the problem of transfer trauma from frequent room transfers based not on care needs but on reimbursement rates. The law now provides that the resident has:

The right to refuse a transfer to another room within the facility, if a purpose of the transfer is to relocate the resident from a portion of the facility that is a skilled nursing facility [i.e., Medicare certified] to a portion of the facility that is not such a skilled nursing facility. 42 USC 1395i-3(c)(1)(A)(x)

There are other provisions regarding intra-facility transfer from a Medicare bed. If you encounter an issue with this type of transfer, read the exact language in the law and requirements and talk with an experienced ombudsman or with your State Long-Term Care Ombudsman.

Nursing homes move residents around regularly in order to respond to their care needs or those of other residents. Residents have very little opportunity to participate in a decision to move, nor do they often have their choice of where to move or of whom their roommate will be. Only a few states protect residents in cases of intra-facility transfer.

There is no specific federal guidance to facilities regarding the process, timing, or content of a notice before there is a change in room or roommate. Unfortunately, residents cannot appeal intra-facility transfers. They do, however, have the right to file a grievance with the facility. Also, ombudsmen have sometimes been successful in arguing that the move would be or has been detrimental to the resident's health or well being.

Notice of Bed-Hold Policy and Readmission [§483.12 (b)]

• Before a facility transfers a resident to a hospital or allows a resident to go on therapeutic leave, the nursing facility must provide written information to a family member that specifies the duration of the bed-hold policy under the State plan and the facility policies regarding bed-hold. Notice must be given at the time of the transfer.
• The facility must also allow a Medicaid recipient to be readmitted to the first available bed in a semi-private room. This provision might affect the decision to hold a bed.

Protection Against Medicaid Discrimination

Discrimination against Medicaid beneficiaries occurs in admissions, transfers, and the provision of services. Some of the practices clearly violate the Social Security Act and Medicaid regulations, while others require development of further protections.

The Nursing Home Reform Amendments prohibit discrimination in treatment of residents and protect residents from fraudulent activities at admission.

Facility Requirements [§483.12 (c) and (d)]

A nursing facility must:

- Have identical policies and practices regarding the provision of services required for all individuals regardless of source of payment.
- Provide information on how to apply for Medicaid and how to receive refunds for previous payments covered by such benefits.
- Not request, require, nor encourage residents to waive their rights to Medicaid.
- Not transfer nor discharge residents solely because they have changed their payment source from private pay to Medicaid.
- Not require another person (commonly known as a “responsible party”) to guarantee payment as a condition of a resident's admission or continued stay.
- Not “charge, solicit, accept or receive gifts, money, donations, or other considerations” as a precondition for admission or continued stay for persons eligible for Medicaid.

Problem Areas

• The acceptance of contributions as a condition of residency in a facility still occurs, particularly among religious nursing homes. Medicaid Fraud Units in several states have prosecuted nursing homes that have solicited donations.

• Financial screening, the practice of requiring potential residents to disclose their financial records as a condition of admission, has been a source of contention. Facilities that have this requirement are using it to ensure that residents will remain private pay for a certain length of time. This discriminatory practice is clearly prohibited by the Nursing Home Reform Law.

• One of the most difficult Medicaid discrimination issues to resolve is the requirement that facilities have identical policies and practices regarding the provision of services mandated under the state plan for all individuals regardless of source of payment. The scope of this provision has yet to be defined or tested. Only a few states have developed regulations to address the problem.

• Nursing homes are required to provide a variety of services to residents, such as nursing, medical, pharmaceutical, dietary, activities, and social services. These services must be of good quality and must meet residents' needs. In order to attract private pay residents and

justify the higher basic rate charged to them, some nursing homes offer more variety and better quality services to private-pay residents, such as different menus, activities, room choices, and amenities.

• Current federal law and regulations require that services be provided to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident. . . . This does not set a basic level of services nor define quality.
Trying to distinguish what services (including scope and quality) must be provided to meet the standard set in the law from those that are considered “enhancements”, is an issue that must be resolved.

Protection from Abuse, Neglect, and Exploitation [13] [§483.13]

All residents in nursing homes are entitled to receive quality care and to live in an environment that improves or maintains the quality of their physical and mental health. This entitlement includes freedom from neglect, abuse, and misappropriation of funds. Neglect and abuse are criminal acts whether they occur inside or outside a nursing home. Residents do not surrender their rights to protection from criminal acts when they enter a facility.

Nursing facilities are required to:

- develop and implement written policies and procedures that prohibit mistreatment, neglect, and abuse of residents and misappropriation of resident property;
- not employ individuals who have been found guilty of abusing, neglecting, or mistreating residents by a court of law; or have had a finding entered into the state nurse aide registry concerning abuse, neglect, mistreatment, or misappropriation of residents’ property;
- thoroughly investigate all alleged violations of mistreatment, neglect, or abuse of residents and misappropriation of property; prevent further potential abuse during the investigation; and report all alleged violations and the results of all investigations to other officials according to state law.

13 The content in this section is from “Abuse and Neglect,” a fact sheet by the National Citizens’ Coalition for Nursing Home Reform. www.nursinghomeaction.org

Abuse

Abuse means causing intentional pain or harm. This includes physical, mental, verbal, psychological, and sexual abuse, corporal punishment, unreasonable seclusion, and intimidation. Examples include:

- Physical abuse from a staff member or an intruder or visitor from outside the facility, including hitting, pinching, shoving, force-feeding, scratching, slapping, and spitting;
- Psychological or emotional abuse —including berating, ignoring, ridiculing, or cursing a resident; threats of punishment or deprivation;
- Sexual abuse — including improper touching or coercion to perform sexual acts;
- Sub-standard care which often results in one or more of the following conditions: immobilization, incontinence, dehydration, pressure sores, and/or depression;
- Rough handling during care giving, medicine administration, or moving a resident.

Neglect

Neglect is the failure to care for a person in a manner, which would avoid harm and pain, or the failure to react to a situation which may be harmful. Neglect may or may not be intentional. For example, a caring aide who is poorly trained may not know how to provide proper care. Examples include:

- Incorrect body positioning — which leads to limb contractures and skin breakdown;
- Lack of toileting or changing of disposable briefs — which causes incontinence and results in residents sitting in urine and feces, increased falls and agitation, indignity and skin breakdown;
- Lack of assistance with eating and drinking—which leads to malnutrition and dehydration;
- Lack of assistance with walking —which leads to lack of mobility;
- Lack of bathing — which leads to indignity and poor hygiene;
- Poor hand washing techniques — which leads to infection;
- Lack of assistance with participating in activities of interest — which leads to withdrawal and isolation;
- Ignoring call bells or cries for help.

Exploitation of Property/Funds

This means the deliberate misplacement or misuse of a resident's belongings or money without the resident's consent. Examples include:

• Not placing resident funds in separate interest-bearing accounts where required;

• Stealing or embezzling a resident's money or personal property, such as jewelry or clothing.

TIPS FOR OMBUDSMAN PRACTICE

- Be alert for potential indicators of abuse, neglect, or exploitation of resident property as you visit residents.

- If there are issues that need investigation or follow-up, proceed as you do with other complaints.

- If you receive an abuse or neglect complaint, use your best efforts to ensure protection of the resident from further abuse or neglect in accordance with the LTCOP policies and procedures in your state.

ENFORCEMENT OF RESIDENTS' RIGHTS

This section discusses some alternatives available to enforce residents' rights in nursing homes.

Federal Survey and Certification Process

The federal survey and certification process under Medicaid is the primary mechanism established for the enforcement of residents' rights. Having residents' rights as part of the federal law gives new emphasis to the rights in enforcement.

However, enforcement is hampered by a lack of understanding and sensitivity to residents' rights by surveyors. Even when surveyors are sensitive to residents' rights, they find them hard to quantify compared with other regulations. Violations are hard to document and hard to prove, and surveyors often fail to understand their seriousness. Correction is difficult to monitor.

The use of resident interviews in the survey process helps sensitize surveyors to residents' rights issues and provides more opportunities for them to observe, learn about, and document violations. Some LTCO Programs have developed brochures for residents and families on how to participate in the survey process. These contain an explanation of the process, how to contact surveyors, and preparing for an interview with a surveyor.

Residents' Rights Specific Penalties

Some states have incorporated nursing home residents' rights into the monetary penalties systems and levy fines for violations. The fine amounts vary and the violations can be difficult to prove. Collecting fines can also be difficult because of a lack of legal support for such actions and because of overwhelming appeal rights given to facilities in most states.

Other Use of the Courts

Advocates have gone to court successfully for restraining orders and injunctions to prevent transfers. Residents have also brought nursing homes to small claims court over lost or stolen possessions and won monetary awards based on facilities' negligence in failing to protect items. The downside is that legal recourse requires proof of damages. It also requires resources and stamina; however, it can be quite effective.

STRENGTHENING RESIDENTS' RIGHTS

There are several basic reasons why many residents are unable to address problems on their own.

- Many residents are unaware of their rights or are unaware of what facilities are required to do.
- Even if they know their rights, many residents are unable to work through the complexities of a problem-solving process because of physical and/or mental limitations or because of a lack of support.
- The process of solving a problem may seem overwhelming.
- Institutional factors, such as isolation, lack of power, and resistance to change can make it difficult for a resident to resolve a problem without assistance.

Three measures that are especially useful in helping residents exercise their rights are discussed in this section: empowering the individual resident, working with resident councils, and working with family councils. The tables on the following pages can be used with each of these groups to help explain some common impediments to exercising residents' rights and to find ways to overcome them.

Table 1 lists a number of the reasons residents are reluctant to assert their rights on their own behalf.

Table 2 lists other obstacles that further impede implementation of residents' rights.

Table 3 lists a number of measures that nursing homes can take to promote and strengthen residents' rights.

A discussion of the role of the ombudsman in empowering individuals and in assisting with resident and family councils follows the three tables. Keep reading for inspiration and very useful tools!

TABLE 1: REASONS RESIDENTS DO NOT ROUTINELY EXERCISE THEIR RIGHTS

1. Residents are intimidated by the idea of appearing in any way to criticize the nursing home.

2. Most residents do not know that they have specified rights and do not know what their rights are in a nursing home.

3. Most residents do not even think about their problems and concerns in any context related to their "rights."

4. Residents have very few opportunities to exercise control over their lives or to have intellectual discussions.

5. Residents have few relationships in which to practice interactive or assertiveness skills or negotiate their rights.

6. Even residents who are aware of their rights must choose their "battles" and often put up with daily violations of their individuality and dignity because:

(a) it requires too much strength to challenge each encounter;
(b) they are easily labeled troublemakers;
(c) they are dependent for their basic care on those very people and, therefore, hesitant to criticize, and, often,
(d) they experience a sense of defeatism.

7. Most residents have come to accept that many of their rights are violated as a part of the daily nursing home routine and, therefore, would never articulate them as problems about which anything can be done.

8. Many residents face a tension between their desire for independence and their need for assistance.

9. Residents often feel more comfortable championing another's problem than asking for help for themselves.

10. Residents face physical, emotional, psychological, social, and/or mental disabilities

that make it difficult for them to voice their concerns.

11. Residents' autonomy is undermined from the start by the very fact that most residents would rather not be in a nursing home; many did not have much of a role or choice in the decision to be there, and most have no other options.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street , NW, Suite 801, Washington, DC 20036

TABLE 2: OBSTACLES TO IMPLEMENTING RESIDENTS' RIGHTS

1. Many residents do not know about or understand their rights.

2. Most residents feel that asserting rights is a negative thing to do.

3. To exercise their rights, residents need the physical care necessary to promote self-reliance and renewed strength, such as: appetizing food to suit their nutritional needs, rehabilitative and restorative therapy, meaningful activities, and freedom from over-medication and over-restraint.

4. Residents who do assert their rights often face tremendous resistance from every level of staff, which discourages them and makes it nearly impossible for them to succeed.

5. Most residents do not have many social supports inside or outside the home to encourage or assist them to live to their fullest.

6. Most resident councils do not receive the leadership development they need to function effectively.

7. Many resident councils meet resistance from staff when they voice concerns.

8. Few families understand residents' rights or know how to empower their relatives to maintain self-determination.

9. Most nursing homes are run in a very regimented, institutional fashion, which leaves little room for individuality, free expression, personal autonomy, or choice.

10. Most nursing homes provide few opportunities to foster relationships.

11. Many staff do not know about nor understand residents' rights.

12. Very few supervisory and managerial personnel understand residents' rights.

13. Sometimes staff feel threatened by "residents' rights."

14. Staff is often poorly trained in residents' rights.

15. Often, staff is not treated in a manner respectful of their own rights.

16. Short staffing prevents staff from taking the time necessary to treat residents respectfully in routine care and treatment.

17. Staff is used to "caring for" residents and do not know how to empower and enable residents to care for themselves.

18. It takes longer to help someone do something for himself/herself than to do it for him/her.

19. Many staff perceive residents' concerns and recommendations as too bothersome and another demand on an already burdensome schedule.

20. Most staff and others see residents' disabilities instead of their abilities.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801, Washington, DC 20036

TABLE 3: HOW FACILITIES CAN PROMOTE AND IMPLEMENT RESIDENTS' RIGHTS

Educate residents and their families about their rights

- Educate and sensitize every level of staff about residents' rights.
- Incorporate resident participation and self-determination into every aspect of nursing home services (e.g., resident advisory committees for food services, activities, housekeeping)
- Provide more support to workers, including sufficient staffing ratios, training, better supervision, dignified working conditions, and increased salaries and benefits.
- Orient nursing assistants to the residents they will work with, and promote relationship building between staff and aides
- Utilize the information and wisdom of residents and their representatives to help develop and conduct training programs for staff.
- Help staff, residents, and families overcome the tension between dependence and empowerment. Residents need assistance, but the help they receive should increase their ability to help themselves.
- Establish a grievance committee comprised of residents, family, staff, and administration.
- Encourage and promote an open exchange of ideas, recommendations, and concerns throughout the facility among residents, families, staff, and administration.
- Build more private rooms for individual residents and public rooms for private use by residents as needed.
- Promote a sense of community within the nursing home. For example, organize activities for each wing and each floor or design activities that promote interaction and intellectual and emotional stimulation.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801,

Resident Councils

Resident councils are organizations within the nursing home or assisted living facility whose members are residents of the home. All residents of the home can participate just by the fact that they reside within the facility. Usually, residents who are able, speak up for those who cannot. Every resident council is different, due to differences in both the residents who participate and in the level of support and responsiveness from the facility.

Resident councils provide a vehicle for resident participation in decision-making and for residents to voice grievances and resolve differences. The Nursing Home Reform Law and federal regulations [§483.15(c)] give strong support and direction for staff in nursing homes to assist in the development and organization of resident councils. No comparable federal law exists for assisted living facilities.

The resident council has grown into a vital force where it has had support. Resident councils have made valuable contributions to decisions within facilities as well as at the state and national policy level. This is particularly true where coalitions of resident councils have helped individual facility councils to function more effectively and have provided a voice for residents on policy issues.

Importance of Resident Councils

Resident councils are important for many reasons. They have become more recognized by facility staff and residents for the important contribution that residents make when given the opportunity to speak for themselves. They provide a forum for residents to:

- Voice their concerns directly to staff.
- Hold the facility accountable.
- Identify problems and their solutions from the residents' perspective.
- Allow residents to recognize staff they feel deserving of recognition.
- Open up discussions on topics of interest to residents.
- Contribute to shaping their world.

In long-term care settings, whether they are large or small communities, resident councils can be a way to foster a feeling of connection to the community. They are a forum for sharing information and being a part of the world in which the resident lives. If the facility sees the value of residents participating in their own world, then the resident council can be a valuable vehicle–not just for improving life in the facility collectively, but also for assisting residents to feel alive individually and in relation to each other.

The Role of the Ombudsman

As an ombudsman, your role is to help develop or support existing resident councils. How you do this will vary with the setting. You may have to begin your work by educating both residents and facility owners to the benefit of having a resident council. You may have to offer assistance with organization and procedures. Ultimately, it will be important for you to treat the resident council as the "go to" place in the facility for addressing community concerns and establishing community connections.

Resident councils vary greatly from home to home. You may find a strong resident council where residents set the agenda and the staff respond to their concerns. A strong resident council is easily recognized; it has broad participation, and residents freely bring up concerns or suggestions for improving the home.

Unfortunately, there are homes that comply with the letter of the law in that they have a resident council, but in reality it is not a true resident council. Some are staff-run and controlled. Residents who attend are wheeled in, read the recreational calendar, fed juice and cookies, then returned to their rooms. In such a home, you will have your work cut out for you!

As an ombudsman visiting in your assigned facility, you will want to learn all you can about the home's resident council.

- Does one exist?
- Is it effective?
- How often does it meet?
- How is it run?
- Who is the president?
- How many residents attend?

One way to begin is to meet with the president of the council and ask permission to attend. Discuss with the president ways that you might be supportive. It is usually best to start out slowly, observing how the group works before offering to help.

Once you have become an invited guest and accepted by the group, you can start to promote the idea of the council as a tool in problem-solving. You will have information to share with residents, but your presence may change the dynamic in the group. Be aware of this, be careful not to overstep. Remember, a resident council is for residents, ombudsmen must always be respectful of this.

Developing a good relationship with the resident council officers will be helpful. As part of your routine, check in with them whenever you are in the facility, and consider them your primary contacts. Ask what they are working on and how you can be helpful. By taking the resident council seriously, you will demonstrate how seriously it should be taken – by residents, families, and staff.

Resident councils in small, assisted living facilities may be less formally arranged than at larger facilities. In smaller homes, residents may meet informally on a regular basis, yet may not recognize the importance of having a forum such as a resident council to air their concerns.

You may spend a great deal of time in the beginning, letting people know why this kind of format works. It is extremely important to enlist the support of the administration and to show how both residents and staff benefit from having this kind of forum.

Avoid over-stepping the council if you attend a meeting. The dynamics of a small setting require a different approach than in a larger facility. Since people get together so often, it may be helpful to encourage residents to have a regular gathering time–perhaps even weekly–that is set aside for formal discussion of issues, experiences, and concerns, with a formal agenda and process for the discussion. Otherwise, it might be hard to distinguish the resident council meeting from any other gathering in the living room. Helping residents take their own council seriously and set aside the time for a real meeting may be a big boost in helping their council work effectively.

Keep in mind that a resident council is an organization that requires organizational skills and structures, as well as leadership skills to function. As we all know, running a meeting is not easy; and if it is done poorly, the meeting can feel like a real bore. No one wants to "waste their time" going to something boring or unproductive. Helping resident council leaders develop their organizational skills can help make the council meetings more productive. Any organization also has an organizing element to it–ways of generating and maintaining interest and involvement are a mainstay to any successful organization.

Some ombudsman programs have helped resident council leaders receive technical assistance in organizational leadership; sometimes through regional meetings of resident council presidents. Of course some people are natural leaders–they will be a great resource to other councils, either at regional gatherings or through visits to each other's homes.

There is a wide selection of written information and videos on resident councils available through your State Ombudsman and other sources. A few excellent resources follow:

Resident Council Resources
Resident Councils Resource Materials
The National Long-Term Care Ombudsman Resource Center
The National Citizens' Coalition for Nursing Home Reform
1828 L Street, Suite 801
Washington, DC 20036
202-332-2275; Fax: 202-332-2949
www.nursinghomeaction.org
www.ltcombudsman.org

How to Organize and Direct an Effective Resident Council
Emmelene W. Kerr, March, 1992
Missouri Long-Term Care Ombudsman Program
Missouri Division of Aging
P.O. Box 570
Jefferson City, MO 65102
1-800-309-3282; (573) 526-0727
www.dhss.mo.gov

Elder Care Rights Alliance
2626 East 82nd Street
Suite 220
Bloomington MN 55425-1381
Phone: 952-854-7304; Fax: 952-854-8535
www.eldercarerights.org

Coalition for the Institutionalized Aged & Disabled
Brookdale Center on Aging
425 E. 25th Street, Room 818
New York, NY 10010
Phone: 212-481-4348; Fax: 212-481-5069
www.ciadny.org

Resident Councils of Washington
220 E. Canyon View Rd.
Belfair, WA 98528-9597
(360) 275-8000
www.residentcouncil.org

TIPS FOR OMBUDSMAN PRACTICE

- Help stimulate and support the development of resident councils in facilities without councils.

- Where a resident council exists, strengthen the functioning of the council if appropriate.

- Provide information and education on a variety of topics at the request of the council.

- Meet with the council regarding problems within the facility.

- Encourage attendance by: Talking it up. Some residents do not routinely go to council meetings for many different reasons. As you visit, ask residents if they attend the council meeting.

- Encourage them to use the council as a way to bring forward concerns. If they are reluctant to do so, find out why. Once you know what the barriers are, you can work with the president to make a plan for overcoming them.

- Attending the resident council meeting yourself. After suggesting to residents that this can be a means to solve problems, let them know that you will attend with them. Many residents will welcome this support. Attend only if invited.

- Come early. Arrive at the facility at least a half-hour before the meeting begins.

- Visit with residents who have told you that they would like to attend. They may initially need this kind of reminder. In some facilities, you may find that staff has not helped them get ready, and your presence is the prompt that is needed.

- Suggesting that residents put it in writing. Some residents will feel more comfortable bringing concerns forward if they have listed their concerns in writing before the meeting. Then at the meeting, they can choose to voice their concerns or read from their list.

- Remember that the council is the residents' group and should meet their needs, not be shaped to serve the ombudsman's needs.

Family Councils

Family councils are groups that meet regularly and whose membership includes family and friends of residents. Like resident councils, there is language in federal law that mandates that the facility provide support and assistance to family councils. [§483.10] However, even with the federal nursing home law supporting family councils, the reality is that few facilities have active family councils. This may be changing. More facilities are seeking Joint Commission on Accreditation of Healthcare Organization accreditation, which requires more active support and encouragement of family councils from the facility.

Family councils provide a needed link to the world outside of the facility for residents. They are especially valuable in the small, assisted living facilities where residents may be hesitant to voice concerns. They can be a buffer for residents having problems with the homes' administration and can provide an oversight from the community that is invaluable.

One of the reasons that family councils do not develop is that family members and friends have limited time and may not be able to both visit their loved one and attend a family council meeting. Unless there is a pressing need, many family members and friends understandably would rather spend their time visiting.

Importance of Family Councils

Family councils can be a vehicle for breaking the isolation of residents and family members. Additionally, they can provide needed validation for family members and residents. Sometimes family members feel as though they are "causing trouble" if they bring forward a complaint. In isolation, a family member may believe that they are the only family experiencing problems. Complaints are far less likely to be brushed aside or blamed on the resident when brought forth by a family council.

It is easy to ignore a complaint when the administrator hears from a lone family member; but when the concern is brought forth in a group setting, there is the public relations need, if nothing else, that will propel the concern forward to resolution. It is true that there is "strength in numbers".

Some facilities hold information-sharing sessions or support groups such as an Alzheimer's support group and label them as a family council. Although they may be very

helpful to family members, they are not what is meant by a family council. Family councils are regular meetings run by family and friends of residents with the support of facility staff. Family councils can be very powerful. Some are completely run by family and friends of residents. Staff can come to their meetings by invitation only!

One family council member felt that the greatest benefit to her was the fact that through the council she had developed friendships with other family members. When she could not visit with her mom, she could call another family member and ask them to look in on her mom. This shared “looking out” for each other contributes to her feeling that her mother is all right even on the rare evening she cannot visit.

There is strength in numbers when voicing complaints or concerns to facility management.

The Role of the Ombudsman

Your role as an ombudsman is to provide support and encouragement as well as educational information to family members. To do this effectively, you need to know what is already in place in the facility. As you begin to visit, ask questions about the family council.

Some questions you might ask are:

- Is there currently a family council?
- If not, has there ever been one, or have there been attempts to start one?
- If so, how often does it meet?
- Who is the president?
- How well attended is it?
- What kind of issues does it deal with?
- Has it been effective?

If there is a family council, you should introduce yourself to the president and offer your services. If you are invited to attend meetings, remember that, just as with resident councils, you are an invited guest and must be respectful of their process.

If the facility you are visiting does not have a family council, you can be instrumental in assisting family members to start one. You can start by informing family members of the benefits of joining together. Some of these benefits include:

- Identifying problems and offering solutions from the resident's perspective.
- Opening up the dialogue between staff and residents and their family members.
- Having input in facility policies that better meet resident needs and desires.
- Providing a buffer for residents who do not feel comfortable identifying problems.
- Providing family members a forum for identifying shared concerns.
- Turning reactive frustration into proactive energy.
- Enhancing a sense of community for both residents and family members.

Just as with resident councils, family councils may need assistance in developing good organizational and leadership skills. Taking on an organizational responsibility on top of their other responsibilities in life can be overwhelming for family members; therefore, family members are likely to participate only if the council seems worthwhile. If a particular incident draws family members' interest (like the change of ownership, key staff, or in how something works at the home), you as ombudsman can play an important role in helping family members stay involved after the initial energy wanes. You do this by working with them on their particular concern in a way that helps them see the long term value of their continued involvement.

Often family members have a very focused view on their own family situation but do not have a larger context for understanding how the facility and the system work. Ombudsmen help bring people together.

As an ombudsman, you can help family members see connections between their concerns and concerns of others; between their concerns and general issues about the facility; or about the system. For example, a family member may be very concerned when a resident's needs are not met. You may know that this is a problem faced by other family members, that it is a function of under-staffing or poor training, or how the management operates. You can explain some of what you know about why the problem exists and the extent of it in a way that helps family members see that they have a common interest in addressing the concern collectively with the facility leadership.

Joint Family Councils

Sometimes family members may want to join together with family members from another facility because there are too few family members from just one facility. At other times, family councils join together because some problems are too large for one family council to tackle. As an ombudsman, you will have knowledge of the concerns of not only one home but of others in the area. If you hear the same concerns voiced by family members from different homes, it most likely surrounds an issue that needs to be addressed at a higher level. You can be instrumental in bringing people together. You can let people know that they are not alone, that others have voiced similar concerns. You can ask them if they have any interest in getting together with others who are concerned. With their permission, you can share their name with others; or if you know that there is enough interest, you can hold open forums where people can come together to voice concerns.

As effective as a family council in a given home can be, joint family councils can be a powerful voice for change. They can affect change in large ways, such as impacting the legislative process to address concerns systemically, or to change policy in the Medicaid office. For example, perhaps a number of family councils are concerned about under-staffing.

They can each address this problem at their own facility. But they may also want to bring the problem of under-staffing throughout the area to the attention of state officials. They might want to become engaged in an effort to increase the minimum staffing level in facilities. Another big concern for many resident and families is the need for privacy. This, too, would need to be tackled on a system level. Perhaps a coalition of family groups would want to advocate for passage of a law requiring all newly-built facilities to have more single rooms.

Joint family groups can become even more powerful by joining other citizen action groups to form coalitions that support needed change. A few excellent resources on family councils follow:

Family Council Resources
Family Education & Outreach:
Final Report
The National Citizens' Coalition for Nursing Home Reform
1828 L Street, Suite 801
Washington, DC 20036
Phone: 202-332-2275; Fax: 202-332-2949
www.nursinghomeaction.org

Nursing Home Family Council Manual
Texas Advocates for Nursing Home Residents
P.O. Box 68
DeSoto, TX 75123
Phone: 972-572-6330; Fax: 972-572-7954
www.tanhr.org

Friends & Relatives of the
Institutionalized Aged, Inc.
18 John Street, Suite 905
New York, NY 10038
Phone: 212-732-4455; Fax: 212-732-6945
www.fria.org

Long Term Care Ombudsman Guide to Developing and Supporting Family Councils and the Family Guide to Effective Family Councils
Robyn Grant, Consultant
The Legal Assistance Foundation of Metropolitan Chicago
111 W. Jackson Boulevard, 3rd Floor
Chicago, IL 60604
Phone: 312-341-1071, ext. 8341
Fax: 312-612-1441
www.lafchicago.org

Elder Care Rights Alliance
2626 East 82nd Street, Suite 220
Bloomington MN 55425-1381
Phone: 952-854-7304; Fax: 952-854-8535
www.eldercarerights.org

Advance directives are written instructions from a decision-capable individual regarding future health care decisions in the event that he/she becomes incapacitated.

LEGAL PROTECTION: DECISION-MAKING MECHANISMS

Advances in health care and unprecedented growth in the number of Americans living to very old age continue to create important new challenges for our society. Principal among these is that modern medical care can extend some individuals' lives beyond the point where they are capable of making decisions or expressing their needs and desires. This section discusses various legal mechanisms to protect an individual's self-determination to the greatest extent possible.

All of the mechanisms discussed are created in state statutes, except for representative payee and the Patient Self-Determination Act. Therefore, mechanisms for establishing power of attorney and guardianship may function differently from state to state.

Presumption

Even when an individual resides in a long-term care facility, relatives and professional caregivers do not have the legal authority to make decisions for him or her unless that authority has been specifically granted. This is true regardless of how incapacitated an individual is. Residents are presumed to be legally capable of making decisions about their care in a long-term care facility.

Advance Directives

A specific way to promote continuing control over decisions is to write advance directives. The directives may specify medical treatment the individual consents to or refuses and may designate a surrogate decision-maker.

Living Will

A living will (or "medical directive) is a legal document through which a person expresses his/her wishes about medical treatment in the event he/she is unable to make those wishes known. It is effective only when an individual is facing a terminal condition and is unable to provide directives to his physician. A living will can be changed or revoked at any time.

A long-term care facility cannot be forced to comply with the terms of a living will. It is obligated, however, to make a reasonable attempt to locate another facility that will comply with an individual's living will.

Power of Attorney[14]

A power of attorney is a legal device that permits one individual the authority to act on behalf of another individual (the principal). The designated person (agent) may be authorized to handle some or all aspects of an individual's life. Common examples of activities a power of attorney might conduct are: banking, buying and selling real estate, incurring expenses, or paying bills. A principal can only develop a power of attorney when the principal is legally competent and capable of expressing her desires regarding this tool.

A power of attorney may:

- restrict duties of the agent by specifying the areas of responsibility/authority;
- be granted for a specified or unspecified length of time;
- be revoked or changed at any time by the individual granting the power of attorney, (the principal.)

Any third party (such as a bank or long-term care facility) who recognizes the power of attorney is not obligated to ask the principal what his or her wishes may be in an area covered by the power of attorney. It is therefore incumbent upon the resident to make his wishes known to the facility or other third party if they differ from that of the agent.

However, in the case of nursing facilities, the Guidance to Surveyors states that:
The rights of the resident that may be exercised by the surrogate or representative include the right to make health care decisions. However, the facility may seek a health care decision (or any other decision or authorization) from a surrogate or representative only when the resident is unable to make the decision. If there is a question as to whether the resident is able to make a health care decision, staff should discuss the matter with the resident at a suitable time and judge how well the resident
understands the information. [Guidelines: §483.10 (a) (3) and (4)]

[14] Much of this section is adapted from: The Alaska Guardianship System. Prepared for: AK Division of Senior Services, Dept. of Administration, by The McDowell Group. Juneau, AK. September 1998.

A power of attorney may be written so that it becomes effective only if, and when, an individual (principal) becomes disabled or mentally incompetent, depending upon the way it is written. Called durable powers of attorney, these documents are more flexible than a living will and can be applied to more situations. The fact that the power of attorney is "durable" means it cannot be revoked once the person becomes incapacitated.

There is no court supervision or any other monitoring of the agent. Therefore there are some risks associated with granting a power of attorney. This is particularly true if a power of attorney is used on behalf of an incapacitated person.

Power of attorney is a shared decision-making tool.

Powers of attorney are often misunderstood—by residents, families, and facilities. It is critical to remember that an individual does NOT give up their rights when a power of attorney is executed. It is intended to be a convenience for an individual. As an ombudsman, you may find yourself advocating for what a resident wants when a facility has relied inappropriately upon a power of attorney. For example, a daughter who holds a financial power of attorney may instruct a facility to restrict visitation with a brother against a resident's wishes.

Patient Self-Determination Act[15]

The Patient Self-Determination Act, passed in 1990 as part of the Congressional Omnibus Budget Reconciliation Act, was an attempt to ensure that health care providers know whether a resident/patient has any advance directives and that consumers are given information about their ability to make such decisions.

This law requires Medicare and/or Medicaid provider organizations (hospitals, nursing facilities, home health agencies, hospices, and prepaid health care organizations) to:

- provide written information to patients at the time of admission concerning an individual's rights under state law to make decisions concerning medical care, including the right to accept/refuse treatment and the right to formulate advance directives.

[15] This section is from the Louisiana LTCOP Manual.

• maintain written policies and procedures with respect to advance directives and to provide written information to patients about such policies.

• document in the individual's medical record whether the individual has an advance directive (the law does NOT require individuals to have advance directives).

• ensure compliance with the requirements of state law respecting advance directives.

• provide education for staff and the community on issues concerning advance directives.

It is important to remember that the law does not require an individual to execute a living will. If they are interested, there a number of basic forms that are readily available that can be used. However, these forms can contain certain common provisions that may not apply to the individual. Ombudsmen should encourage individuals who express an interest in living wills to think about what they do want as well as what they do not want. It is very important for an individual to be sure that the living will document reflects the person's individual wishes.

Representative Payee

The Social Security Administration uses "representative payee" to mean an individual who agrees to accept Social Security payments on another person's behalf. The payee must agree to use the funds to meet the basic needs of the person entitled to the benefit.

There is a potential for abuse and exploitation due to a lack or regulations, oversight, or independent monitoring.

Often referred to as simply "payee," the representative payee may also collect the individual's public assistance, dividends from Native American corporations, veteran's benefits, and other wages or retirement funds if the beneficiary agrees to the arrangement. The funding agencies have forms that must be completed in order to designate someone as representative payee. The individual designated as representative payee can be changed whenever the individual receiving the payment/benefit chooses. For convenience, facilities are often named as representative payee.

Payees have certain reporting requirements depending upon the benefit(s) they collect on behalf of the client. The Social Security Administration requires a yearly report outlining

how the payee spent the individual's benefits and the amount of funds remaining. The Veteran's Administration requires similar reports.

Guardianship

Guardianship is the process of legally taking away rights from a person who is unable to make decisions for him/herself. The person who is appointed by a court to make those decisions is called a "guardian." A person who has a guardian who makes decisions for him/her is called a "ward."

The process of getting a guardianship of another person is difficult. There are legal protections afforded to the allegedly incapacitated person (the respondent), such as the right to legal representation at the hearing. Another protection is a requirement that the court consider alternatives to guardianship. Hence, guardianship is used as the last resort to promote and protect the well-being of an incapacitated person.

Guardianship can be full or limited. A full guardianship is sometimes called "legal death" because it means that all decisions are left to the guardian. A limited guardianship may give the guardian control over only certain areas, such as financial decisions.

Guardianships can also be granted on a temporary or emergency basis if a court is convinced that the individual is at immediate risk.

A guardianship can be terminated by the court if there is evidence that no guardianship or a less-restrictive guardianship is needed. If a guardian is not acting in the best interest of the ward, the court can choose to appoint a different individual as guardian.

Guardians are required to file reports with the court at specified times. Guardians are also required to report to the court when there are significant changes in the ward's situation.

Even if an individual is under full guardianship, their wishes, if they are able to state them, must still be considered. The Guidance to Surveyors states that:

In the case of a resident who has been formally declared incompetent by a court, lack of capacity is presumed. Notwithstanding the above, if such a resident can understand the situation and express a preference, the resident should be informed and his/her wishes respected to the degree practicable. [Guidelines: §483.10 (a) (3) and (4)]

Tips for Ombudsman Practice

As a LTCO, it is important for you to know the differences in the various types of decision-making mechanisms available in your state. Your role is to model residents' rights. One primary way is to support each resident's right to make decisions and to participate in planning their care and treatment. More information about how to do this is discussed in the problem-solving section of the curriculum materials. Ombudsman skills in this area will be continually refined through working on cases and additional training. A few basic tips for practice follow.

TIPS FOR OMBUDSMAN PRACTICE

Help support a resident's decision-making. Provide information about the range of decision-making mechanisms that are available and refer individuals to the appropriate resources for assistance. Be alert in situations where terms like "resident representative," "power of attorney," or "guardian" may be used interchangeably. Verify what mechanism, if any, exists and the extent of what that mechanism covers if necessary to address a resident's concerns.

If a case arises with a resident who has a guardian, as an ombudsman, you will work with or through the guardian in most situations. There are three exceptions:

1. The complaint is about the guardian or some action of the guardian.
2. The complaint is about the issues of whether the guardian is needed.
3. The guardianship is a limited one (the resident retains the right to make some decisions).

With these types of cases, it may be advisable to seek legal advice from an appropriate agency. Remember that residents may be able to clearly communicate what they want through behavior. The law, regulations, and Guidance to Surveyors support involving the resident in making decisions about their care and life to the extent that is practicable.

As an ombudsman, you are the primary model many individuals will have for supporting and encouraging residents in exercising decision-making in their daily lives. Be vigilant about checking with the resident as an initial step in working on a case. Then either empower and assist the resident in resolving the issue, or take your direction from the resident.

APPENDIX A

FEDERAL RESIDENTS' RIGHTS PROVISIONS

* Excerpted from a formatted version of the law developed by Leigh Ann Clark in the Georgia Long Term Care Ombudsman Program Manual.

Federal Law – Regulation of Nursing Facilities
Residents' Rights Excerpt from 42 USC Sec. 1396r*
TITLE 42 - THE PUBLIC HEALTH AND WELFARE
CHAPTER 7 - SOCIAL SECURITY
SUBCHAPTER XIX - GRANTS TO STATES FOR MEDICAL ASSISTANCE PROGRAMS
Sec. 1396r. Requirements for Nursing Facilities
(c) Requirements relating to residents' rights
(1) General rights
(A) Specified rights

A nursing facility must protect and promote the rights of each resident, including each of the following rights:

(i) Freedom of choice
The right to choose a personal attending physician, to be fully informed in advance about care and treatment, to be fully informed in advance of any changes in care or treatment that may affect the resident's well-being, and (except with respect to a resident adjudged incompetent) to participate in planning care and treatment or changes in care and treatment.

(ii) Freedom from restraints
The right to be free from physical or mental abuse, corporal punishment, involuntary seclusion, and any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms.

Restraints may only be imposed:

(I) to ensure the physical safety of the resident or other residents, and

(II) upon the written order of a physician that specifies the duration and circumstances under which the restraints are to be used (except in emergency circumstances specified by the Secretary until such an order could reasonably be obtained).

(iii) Privacy

The right to privacy with regard to accommodations, medical treatment, written and telephonic communications, visits, and meetings of family and of resident groups.

(iv) Confidentiality

The right to confidentiality of personal and clinical records and to access to current clinical records of the resident upon request by the resident or the resident's legal representative, within 24 hours (excluding hours occurring during a weekend or holiday) after making such a request.

(v) Accommodation of needs

The right to:

(I) reside and receive services with reasonable accommodation of individual needs and preferences, except where the health or safety of the individual or other residents would be endangered, and

(II) receive notice before the room or roommate of the resident in the facility is changed.

(vi) Grievances

The right to voice grievances with respect to treatment or care that is (or fails to be) furnished, without discrimination or reprisal for voicing the grievances and the right to prompt efforts by the facility to resolve grievances the resident may have, including those with respect to the behavior of other residents.

(vii) Participation in resident and family groups

The right of the resident to organize and participate in resident groups in the facility and the right of the resident's family to meet in the facility with the families of other residents in the facility.

(viii) Participation in other activities

The right of the resident to participate in social, religious, and community activities that do not interfere with the rights of other residents in the facility.

(ix) Examination of survey results

The right to examine, upon reasonable request, the results of the most recent survey of the facility conducted by the Secretary or a State with respect to the facility and any plan of correction in effect with respect to the facility.

(x) Refusal of certain transfers

The right to refuse a transfer to another room within the facility, if a purpose of the transfer is to relocate the resident from a portion of the facility that is not a skilled nursing facility (for purposes of subchapter XVIII of this chapter) to a portion of the facility that is such a skilled nursing facility.

(xi) Other rights

Any other right established by the Secretary. Clause (iii) shall not be construed as requiring the provision of a private room. A resident's exercise of a right to refuse transfer under clause (x) shall not affect the resident's eligibility or entitlement to medical assistance under this subchapter or a State's entitlement to Federal medical assistance under this subchapter with respect to services furnished to such a resident.

(B) Notice of rights

A nursing facility must -

(i) inform each resident, orally and in writing at the time of admission to the facility, of the resident's legal rights during the stay at the facility and of the requirements and procedures for establishing eligibility for medical assistance under this subchapter, including the right to request an assessment under section 1396r-5(c)(1)(B) of this title;

(ii) make available to each resident, upon reasonable request, a written statement of such rights (which statement is updated upon changes in such rights) including the notice (if any) of the State developed under subsection (e)(6) of this section;

(iii) inform each resident who is entitled to medical assistance under this subchapter

(I) at the time of admission to the facility or, if later, at the time the resident becomes eligible for such assistance, of the items and services (including those specified under section 1396a(a)(28)(B) of this title) that are included in nursing facility services under the State plan and for which the resident may not be charged (except as permitted in section 1396o of this title), and of those other items and services that the facility offers and for which the resident may be charged and the amount of the charges for such items and services, and

(II) of changes in the items and services described in subclause (I) and of changes in the charges imposed for items and services described in that subclause; and

(iv) inform each other resident, in writing before or at the time of admission and periodically during the resident's stay, of services available in the facility and of related charges for such services, including any charges for services not covered under subchapter XVIII of this chapter or by the facility's basic per diem charge.

The written description of legal rights under this subparagraph shall include a description of the protection of personal funds under paragraph (6) and a statement that a resident may file a complaint with a State survey and certification agency regarding resident abuse and neglect and misappropriation of resident property in the facility.

(C) Rights of incompetent residents

In the case of a resident adjudged incompetent under the laws of a State, the rights of the resident under this subchapter shall devolve upon, and, to the extent judged necessary by a court of competent jurisdiction, be exercised by, the person appointed under State law to act on the resident's behalf.

(D) Use of psychopharmacologic drugs

Psychopharmacologic drugs may be administered only on the orders of a physician and only as part of a plan (included in the written plan of care described in paragraph (2)) designed to eliminate or modify the symptoms for which the drugs are prescribed and only if, at least annually an independent, external consultant reviews the appropriateness of the drug plan of each resident receiving such drugs.

(2) Transfer and discharge rights

(A) In general

A nursing facility must permit each resident to remain in the facility and must not transfer or discharge the resident from the facility unless the:

(i) transfer or discharge is necessary to meet the resident's welfare and the resident's welfare cannot be met in the facility;

(ii) transfer or discharge is appropriate because the resident's health has improved sufficiently so the resident no longer needs the services provided by the facility;

(iii) safety of individuals in the facility is endangered;

(iv) health of individuals in the facility would otherwise be endangered;

(v) resident has failed, after reasonable and appropriate notice, to pay (or to have paid under this subchapter or subchapter XVIII of this chapter on the resident's behalf) for a stay at the facility; or

(vi) facility ceases to operate.

In each of the cases described in clauses (i) through (iv), the basis for the transfer or discharge must be documented in the resident's clinical record. In the cases described in clauses (i) and (ii), the documentation must be made by the resident's physician, and in the case described in clause (iv) the documentation must be made by a physician. For purposes of clause (v), in the case of a resident who becomes eligible for assistance under this subchapter after admission to the facility, only charges which may be imposed under this subchapter shall be considered to be allowable.

(B) Pre-transfer and pre-discharge notice

(i) In general

Before effecting a transfer or discharge of a resident, a nursing facility must -

(I) notify the resident (and, if known, an immediate family member of the resident or legal representative) of the transfer or discharge and the reasons therefore,

(II) record the reasons in the resident's clinical record (including any documentation required under subparagraph A) and

(III) include in the notice the items described in clause (iii).

(ii) Timing of notice

The notice under clause (i)(I) must be made at least 30 days in advance of the resident's transfer or discharge except in:

(I) a case described in clause (iii) or (iv) of subparagraph (A);

(II) a case described in clause (ii) of subparagraph (A), where the resident's health improves sufficiently to allow a more immediate transfer or discharge;

(III) a case described in clause (i) of subparagraph (A), where a more immediate transfer or discharge is necessitated by the resident's urgent medical needs; or

(IV) a case where a resident has not resided in the facility for 30 days.

In the case of such exceptions, notice must be given as many days before the date of the transfer or discharge as is practicable.

(iii) Items included in notice

Each notice under clause (i) must include:

(I) for transfers or discharges effected on or after October 1, 1989, notice of the resident's right to appeal the transfer or discharge under the State process established under subsection (e)(3) of this section;

(II) the name, mailing address, and telephone number of the State long-term care ombudsman (established under title III or VII of the Older Americans Act of 1965 (42 U.S.C. 3021 et seq., 3058 et seq.) in accordance with section 712 of the Act (42 U.S.C. 3058g));

(III) in the case of residents with developmental disabilities, the mailing address and telephone number of the agency responsible for the protection and advocacy system for developmentally disabled individuals established under part C of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6041 et seq.); and

(IV) in the case of mentally ill residents (as defined in subsection (e)(7)(G)(i) of this section), the mailing address and telephone number of the agency responsible for the protection and advocacy system for mentally ill individuals established under the Protection and Advocacy for Mentally Ill Individuals Act (42 U.S.C. 10801 et seq.).

(C) Orientation

A nursing facility must provide sufficient preparation and orientation to residents to ensure safe and orderly transfer or discharge from the facility.

(D) Notice on bed-hold policy and readmission

(i) Notice before transfer

Before a resident of a nursing facility is transferred for hospitalization or therapeutic leave, a nursing facility must provide written information to the resident and an immediate family member or legal representative concerning -

(I) the provisions of the State plan under this subchapter regarding the period (if any) during which the resident will be permitted under the State plan to return and resume residence in the facility, and

(II) the policies of the facility regarding such a period, which policies must be consistent with clause (iii).

(ii) Notice upon transfer

At the time of transfer of a resident to a hospital or for therapeutic leave, a nursing facility must provide written notice to the resident and an immediate family member or legal representative of the duration of any period described in clause (i).

(iii) Permitting resident to return

A nursing facility must establish and follow a written policy under which a resident:

(I) who is eligible for medical assistance for nursing facility services under a State plan,

(II) who is transferred from the facility for hospitalization or therapeutic leave, and

(III) whose hospitalization or therapeutic leave exceeds a period paid for under the State plan for the holding of a bed in the facility for the resident, will be permitted to be readmitted to the facility immediately upon the first availability of a bed in a semiprivate room in the facility if, at the time of readmission, the resident requires the services provided by the facility.

(E) Information respecting advance directives

A nursing facility must comply with the requirement of section 1396a(w) of this title (relating to maintaining written policies and procedures respecting advance directives).

(3) Access and visitation rights

A nursing facility must:

(A) permit immediate access to any resident by any representative of the Secretary, by any representative of the State, by an ombudsman or agency described in subclause (II), (III), or (IV) of paragraph (2)(B)(iii), or by the resident's individual physician;

(B) permit immediate access to a resident, subject to the resident's right to deny or withdraw consent at any time, by immediate family or other relatives of the resident;

(C) permit immediate access to a resident, subject to reasonable restrictions and the resident's right to deny or withdraw consent at any time, by others who are visiting with the consent of the resident;

(D) permit reasonable access to a resident by any entity or individual that provides health, social, legal, or other services to the resident, subject to the resident's right to deny or withdraw consent at any time; and

(E) permit representatives of the State ombudsman (described in paragraph (2)(B)(iii)(II)), with the permission of the resident (or the resident's legal representative) and consistent with State law, to examine a resident's clinical records.

(4) Equal access to quality care

(A) In general

A nursing facility must establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services required under the State plan for all individuals regardless of source of payment.

(B) Construction

(i) Nothing prohibiting any charges for non-Medicaid patients

Subparagraph (A) shall not be construed as prohibiting a nursing facility from charging any amount for services furnished, consistent with the notice in paragraph (1)(B) describing such charges.

(ii) No additional services required

Subparagraph (A) shall not be construed as requiring a State to offer additional services on behalf of a resident than are otherwise provided under the State plan.

(5) Admissions policy

(A) Admissions

With respect to admissions practices, a nursing facility must:

(i) (I) not require individuals applying to reside or residing in the facility to waive their rights to benefits under this subchapter or subchapter XVIII of this chapter, (II) not require oral or written assurance that such individuals are not eligible for, or will not apply for, benefits under this subchapter or subchapter XVIII of this chapter, and (III) prominently display in the facility written information, and provide to such individuals oral and written information, about how to apply for and use such benefits and how to receive refunds for previous payments covered by such benefits;

(ii) not require a third party guarantee of payment to the facility as a condition of admission (or expedited admission) to, or continued stay in, the facility; and

(iii) in the case of an individual who is entitled to medical assistance for nursing facility services, not charge, solicit, accept, or receive, in addition to any amount otherwise required to be paid under the State plan under this subchapter, any gift, money, donation, or other consideration as a precondition of admitting (or expediting the admission of) the individual to the facility or as a requirement for the individual's continued stay in the facility.

(B) Construction

(i) No preemption of stricter standards

Subparagraph (A) shall not be construed as preventing States or political subdivisions therein from prohibiting, under State or local law, the discrimination against individuals who are entitled to medical assistance under the State plan with respect to admissions

practices of nursing facilities.

(ii) Contracts with legal representatives

Subparagraph (A)(ii) shall not be construed as preventing a facility from requiring an individual, who has legal access to a resident's income or resources available to pay for care in the facility, to sign a contract (without incurring personal financial liability) to provide payment from the resident's income or resources for such care.

(iii) Charges for additional services requested

Subparagraph (A)(iii) shall not be construed as preventing a facility from charging a resident, eligible for medical assistance under the State plan, for items or services the resident has requested and received and that are not specified in the State plan as included in the term "nursing facility services".

(iv) Bona fide contributions

Subparagraph (A)(iii) shall not be construed as prohibiting a nursing facility from soliciting, accepting, or receiving a charitable, religious, or philanthropic contribution from an organization or from a person unrelated to the resident (or potential resident), but only to the extent that such contribution is not a condition of admission, expediting admission, or continued stay in the facility.

(6) Protection of resident funds

(A) In general

The nursing facility:

(i) may not require residents to deposit their personal funds with the facility, and

(ii) upon the written authorization of the resident, must hold, safeguard, and account for such personal funds under a system established and maintained by the facility in accordance with this paragraph.

(B) Management of personal funds

Upon written authorization of a resident under subparagraph (A)(ii), the facility must manage and account for the personal funds of the resident deposited with the facility as follows:

(i) Deposit

The facility must deposit any amount of personal funds in excess of $50 with respect to a resident in an interest bearing account (or accounts) that is separate from any of the facility's operating accounts and credits all interest earned on such separate account to such account. With respect to any other personal funds, the facility must maintain such funds in a non-interest bearing account or petty cash fund.

(ii) Accounting and records

The facility must assure a full and complete separate accounting of each such resident's personal funds, maintain a written record of all financial transactions involving the personal funds of a resident deposited with the facility, and afford the resident (or a legal representative of the resident) reasonable access to such record.

(iii) Notice of certain balances

The facility must notify each resident receiving medical assistance under the State plan under this subchapter when the amount in the resident's account reaches $200 less than the dollar amount determined under section 1382(a)(3)(B) of this title and the fact that if the amount in the account (in addition to the value of the resident's other nonexempt resources) reaches the amount determined under such section the resident may lose eligibility for such medical assistance or for benefits under subchapter XVI of this chapter.

(iv) Conveyance upon death Upon the death of a resident with such an account, the facility must convey promptly the resident's personal funds (and a final accounting of such funds) to the individual administering the resident's estate.

(C) Assurance of financial security

The facility must purchase a surety bond, or otherwise provide assurance satisfactory to

the Secretary, to assure the security of all personal funds of residents deposited with the facility.

(D) Limitation on charges to personal funds

The facility may not impose a charge against the personal funds of a resident for any item or service for which payment is made under this subchapter or subchapter XVIII of this chapter.

(7) Limitation on charges in case of Medicaid-eligible individuals

(A) In general

A nursing facility may not impose charges, for certain Medicaid-eligible individuals for nursing facility services covered by the State under its plan under this subchapter, that exceed the payment amounts established by the State for such services under this subchapter.

(B) "Certain Medicaid-eligible individual" defined

In subparagraph (A), the term "certain Medicaid-eligible individual" means an individual who is entitled to medical assistance for nursing facility services in the facility under this subchapter but with respect to whom such benefits are not being paid because, in determining the amount of the individual's income to be applied monthly to payment for the costs of such services, the amount of such income exceeds the payment amounts established by the State for such services under this subchapter.

(8) Posting of survey results

A nursing facility must post in a place readily accessible to residents, and family members and legal representatives of residents, the results of the most recent survey of the facility conducted under subsection (g) of this section.

APPENDIX B

ASSESSMENT AND CARE PLANS

THE KEY TO GOOD CARE

ASSESSMENT and CARE PLANNING: THE KEY TO GOOD CARE

Consumer Information Sheet

Each and every person in a nursing home has a right to good care under the 1987 Federal Nursing Home Reform Law. The law, which is part of the Social Security Act, says that a nursing home must help each resident “attain or maintain” his or her highest level of well being - physically, mentally, and emotionally. To give good care, staff must assess and plan care to support each resident’s life-long patterns, current interests, strengths, and needs. Care planning conferences are a valuable forum for residents and families to voice concerns, ask questions, give suggestions, learn nursing home strategies, and give staff information (such as resident background and daily routine). This requirement in the law is vital to making sure residents get good care.

Resident Assessment

Assessments gather information about the health and physical condition of a resident and how well a resident can take care of themselves. This includes assessing when help may be needed in activities of daily living (ADLs) or “functional abilities” such as walking, eating, dressing, bathing, seeing, hearing, communicating, understanding, and remembering. Assessments also should examine a residents’ habits, activities, and relationships in order to help him or her live more comfortably and feel at home in the facility.

The assessment helps staff to be aware of strengths of the resident and also determine the reason for difficulties a resident is having. An example of where a good assessment helps: A resident begins to have poor balance. This could be the result of medications, sitting too much, weak muscles, poorly fitting shoes, or a urinary or ear infection. Staff must find out the cause of a problem in order to give good treatment. Figuring out the cause is much easier with a good assessment.

Assessments must be done within 14 days of the resident’s admission to a nursing home (or 7 days for Medicare residents) and at least once a year after that. Reviews are held every three months and when a resident’s condition changes.

Plan of Care

After the assessment is completed, the information is analyzed and a care plan is developed to address all the needs and concerns of the resident. The initial care plan must be completed within seven days after the assessment. The care plan is a strategy for how the staff will help a resident every day. This care plan says what each staff person will do and when it will happen (for example, a nursing assistant will help Mrs. Jones walk to each meal to build her strength). Care plans must be reviewed regularly to make sure they work and must be revised as needed. For care plans to work, residents must feel they meet their needs and must be comfortable with them.

Care Planning Conference

The care plan is developed by an interdisciplinary team -- nurse, nurse aide, activities and dietary staff, and social worker, with critical input from the resident and/or family members. All participants discuss the resident's care at a Care Plan Conference to make certain that all medical and non-medical issues, including meals, activities, therapies, personal schedule, medical and nursing care, and emotional needs are agreed upon and addressed. Resident and family member concerns should be listened to by staff and addressed in the care plan. A good Care Plan Conference takes time. It should not be rushed, and could take at least one hour. Every 90 days after development of the initial plan, or whenever there is a big change in a resident's physical or mental health, a Care Plan Conference is held to determine how things are going and if changes need to be made.

Good Care Plans Should

- Be specific to that resident;
- Be followed as an important guideline for providing good care for the resident;
- Be written so that everyone can understand it and know what to do;
- Reflect the resident's concerns and support his or her well-being;
- Use a team approach involving a wide variety of staff and outside referrals as needed;
- Assign tasks to specific staff members;
- Be re-evaluated and revised routinely.

Steps for Residents and Family Participation in Care Planning

Residents and family members have the right to be involved in the care plan conference in order to make choices about care, services, daily schedule, and life in the nursing home. Even if a resident has dementia, involve them in care planning as much as possible. Be aware that they may understand and communicate at some level and help the staff to find ways to communicate and work with them. They can express when they hurt or suffer if they are actively listened to. Participating in care plan conferences is a way to be heard, raise questions, and come to a clear agreement with the facility about how the resident will be cared for.

Before the meeting:

- Ask staff to hold the meeting at a convenient time for you and/or your family member;
- Ask for a copy of the current care plan (if one already exists) so that you can examine each aspect thoughtfully.
- Know about or ask the doctor or staff about your or your loved one's condition, care, and treatment.
- Plan your list of questions, needs, problems,
- and goals, and
- Think of examples and reasons to support changes you recommend in the care plan.

During the meeting:

- Make sure the resident is involved and listened to carefully.
- Discuss options for treatment and for meeting your needs and preferences;
- Ask questions if you need terms or procedures explained to you;
- Be sure you understand and agree with the care plan and feel it meets your needs;
- Ask for a copy of the care plan;
- Find out who to talk to if changes in the care plan are needed, and;
- Find out who to talk to if there are problems with the care being provided.

After the meeting:

- Monitor whether the care plan is being followed;
- Inform the resident's doctor about the care plan if s/he was not directly involved;
- Talk with nurse aides, staff or the doctor about the care plan, and;
- Request another meeting if the plan is not being followed.
- See NCCNHR's "Resolving Problems in Nursing Homes" for additional information.

If you are interested in learning more, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) has several publications that may be of interest. Call 202-332-2275 for a publication list or visit the website at www.nursinghomeaction.org

.. Nursing Homes: Getting Good Care There
.. Avoiding Physical Restraint Use - consumer booklet
.. Avoiding Drugs Used as Chemical Restraints - consumer booklet
.. Using Resident Assessment and Care Planning: An Advocacy Tool for Residents and their Advocates

1828 L Street, Suite 801, Washington, D.C. 20036.
Tel. (202) 332-2275
Fax. (202) 332- 2949
Email: nccnhr@nccnhr.org
Website: www.nursinghomeaction.org

APPENDIX C

FREEDOM FROM RESTRAINTS

CONTEXT FOR FREEDOM FROM PHYSICAL OR CHEMICAL RESTRAINTS USED FOR DISCIPLINE OR CONVENIENCE[16]

Issue:Context for Advocacy

Resident view of physical restraints (Strumpf &Evans, 1988)

Research shows that restrained residents suffer greatly: "I feel like a prisoner." "Why are they punishing me?" "I feel as if my chest is being crushed." "I can't get to the toilet and I wet my bed."

Physical harm from physical restraint use (Burger, 1993)

Be proactive with residents, families, and staff about the harm (risk) that may occur. Restraints can negatively affect every system of the body causing decreased appetite (malnutrition), dehydration, pneumonia, urinary tract infections, constipation, incontinence, decreased bone strength, decreased muscle strength, contracted muscles, bruising/cuts/redness of skin, pressure sores, fall-related injuries, death by asphyxiation.

Emotional harm from physical restraint use (Burger, 1993)

A restrained resident feels isolated and dehumanized suffering:
mental distress including agitation, calling out, depression; withdrawal from others and from surroundings; decreased participation in ctivities; inability to move around or to get to the bathroom; more problems with sleep; reduced contact with friends, family and doctors.

Less staff to care for non-restrained residents (Charles Phillips,1993)

If caregivers are to prevent these poor physical and psychological outcomes, it takes more staff to care for restrained residents than non-restrained. (e.g. turning, toileting, getting water and food, doing exercises to keep bones and muscles strong). Most facilities do not have the staff to provide these kinds of preventive services.

Frail, older residents, often with dementia are most often restrained.
(Evans and Strumpf, 1989)

The reason for restraining is usually unsafe mobility, wandering, confusion and agitation. These issues can always be addressed by thorough assessment (using the RAP on physical restraints), individualized care planning to strengthen mobility, providing a safe place to wander, lowering beds and side rails, and knowing the details of a person's life to provide activities and approaches to care familiar to each resident.

16 The Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87. S. G. Burger, National Long-Term Care Ombudsman Resource Center, NCCNHR. 2005.

Bedrails can be a physical restraint
(Hospital Bed Safety Workgroup)

Clinical research suggests that bed rails may not be benign safety devices. For example, evidence indicates that half-rails pose a risk of entrapment and full rails pose a risk of entrapment. Falls also occur when patients climb over the rails or footboards.17,18 Recognizing this risk, the U.S. Food and Drug Administration (FDA) and CMS have acted to reduce the likelihood of injuries related to bed rails. The FDA MedWatch Reporting Program receives reports of entrapment hazards. In 1995 the FDA issued a Safety Alert entitled, "Entrapment Hazards with Hospital Bed Side Rails." In 1997, the FDA authored an article, based on the reported hospital bed adverse events which identified potential risk factors and entrapment locations about the hospital bed. The FDA continues to receive reports of patient deaths and injury that provide documentation of patient entrapment.

Psychoactive drugs

There are four classes of psychoactive drugs: Antipsychotics (to treat hallucinations, delusions), sedative/hypnotics (to treat sleep disturbances); Anxiolytic (antianxiety drugs); and antidepressants (to treat depression). These drugs can improve the quality of life for residents who need them; however, all drugs pose both risks and benefits.

What are chemical restraints? (Burger, 1993)

While CMS defines chemical restraints as drugs used for discipline or convenience, advocates can also think of them a "psychoactive drugs used to treat behavioral symptoms in place of good care." Older people should take as few drugs as possible, because the more drugs they take the greater the possibility of suffering a poor outcome. Psychoactive drugs can have serious and life threatening side effects.

Like physical restraints, chemical restraints may lead to poor outcomes.
(Burger, 1993)

Psychoactive drugs may cause falls, fractured hips, inability to urinate, development of pressure sores, infections, dry mouth, repetitious movements of the lips, tongue, head, fingers, and toes, blurred vision, constipation, rigidity like Parkinson's, increased agitation rather than decreased. The person may think, talk or move more slowly and lose the ability to care for himself. He may sleep through meals.

Behavioral Symptoms are expressions of an unmet need
(Burger, 1993)

People, who are unable to use words due to a medical condition such as dementia, express themselves through actions. These symptoms include wandering, agitation, screaming, spitting, swearing and many others that are expressions of distress. From the resident's perspective, he is expressing an unmet need. For families, friends and caregivers, the challenge is to discover the unmet need and deliver the care to meet it. (e.g. constant movement or moaning might signal untreated pain, lashing out at caregivers many mean the resident is frightened of the way care is given, trying to leave a facility may mean the resident is trying to meet her children after school-a lifelong habit from the past, repeatedly getting up out of a chair may be a need for water or to go to the bathroom.)

Labels mask the unmet need and increase the use of chemical restraints
(Burger, 1993)

Sometimes caregivers use the term "behavior problem" to describe a resident's actions. Even the 2002 CMS RAP on behaviors uses that term. By labeling someone as a "behavior problem," the cause of the distress is masked. It blames the resident for the symptoms of a disease process. If the symptom such as hitting a caregiver who frightens a resident is treated with a chemical restraint, the cause of the symptom, or unmet need, is masked. A change in caregivers or training and supervision of the caregiver is the appropriate approach.

In depth assessment and individualized care reduce chemical restraint use, including antidepressants.
(Burger, 1993 and Burger et al, 2001)

The MDS identifies symptoms and the RAPs on physical and chemical restraints provide the process for systematically ruling out causes of behaviors. Another adjunct to identifying unmet needs is the Appendix in "Nursing Home Getting Good Care There," entitled, "What I Want You To Know About My Mother."
One of the Pioneering facilities uses that on admission with every resident because it provides the details of a person's life. For example, a resident with Parkinson's and an unsteady gait and some dementia, escaped from the facility every morning. His lifelong routine was to arise early, eat a good breakfast, and head outside for a day of work. The nurse asked the doctor for a drug order for agitation. After the drug was given, the family became alarmed at the droopy appearance of this active man. The facility had provided nothing for him to do, until the family provided this lifelong information. The outside maintenance man was trained as a nurse aide and the two worked together each morning. No drug was needed.

Another resident under similar circumstances might have reacted to the situation with a major depression. An antidepressant would have been a chemical restraint, because more appropriate care could be provided.

Staffing and chemical restraint use (OIG 2001)

(excluding antidepressants) is appropriate and not a chemical restraint. NCCNHR reviewed two of the homes mentioned and related it to self reported staffing. The facility in Idaho with 27% drug use among the residents with behavioral symptoms (with everything from schizophrenia to dementia) had high staffing of 4.04 hours per resident per day (hprd) and used in depth assessment and individualized care. The facility in Maryland that had a 65% drug use in this population had low staffing of 3.38 hprd and was not described as using in depth assessment or individualized care.

Pain identification and treatment: an unmet need (Brown University, 2001)

Research has shown that of those who had persistent or excruciating pain on consecutive assessments, 41% still had pain on the second assessment. Pain is not treated. This statistic is a very understated number because until recently those with dementia were not included. It was assumed that their symptoms were a result of the dementia. Not so, pain is real for those with dementia. Facilities are reporting a decrease in psychotropic drug use, when pain is identified and treated.

Pioneering approaches to care reduce the need for antidepressants (Crestview Nursing Home, 2003)

Facilities that use pioneering approaches to care and have stable staff report a decrease over time in antidepressants. These drugs, like all drugs, are useful for treating serious mental illness. A depression caused by basic unmet needs such as not being taken to the bathroom or being told "you have a diaper on" or having nothing to do should not be treated with an antidepressant. The philosophy and approach to care must change. Remember polypharmacy is a dangerous for frail, older, and often demented individuals.

APPENDIX D: RESOURCES

RESOURCES ON RESIDENTS' RIGHTS AND QUALITY OF LIFE[19]

[19] From An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87, revised 2005.

Books and Reports

An Ombudsman's Guide to The Nursing Home Reform Amendments of OBRA'87. Revised 2005. Burger, S. The National Long-Term Care Ombudsman Resource Center of the National Citizens' Coalition for Nursing Home Reform, 1828 L St., NW, Suite 801, Washington, DC 20036. www.ltcombudsman.org

Nursing Homes: Getting Good Care There. Burger, S., Hunt, S., Frank, B. and Fraser, V. Impact Press, 2nd Edition, 2001. Includes chapter on residents' rights and quality of life. Also includes a piece by Carter Catlett Williams on "What You Should Know About My Mother." Some nursing homes use this on admission to gather information about each resident.

Person Centered Care: A Model for Nursing Homes, Rantz, Marilyn and Flesner, Marcia American Nurses Association, Washington, D.C. order at www.nursingworld.org or call 800-637-0323. (A Story of Professional Commitment: A Study of an Exemplar Long-Term Care Facility) (First book on a Pioneer Network home and how it operates).

Getting Started: A Pioneering Approach to Long Term Care Culture Change. Misiorski. Sue, RN Springer Publishing, 2004. (A how to for Pioneer Network Practices with teaching modules).

Bathing without a Battle: Personal Care of Individuals with Dementia. Barrick, A; Rader, J; Hoeffer, B; and Sloane, P., Springer Series in Geriatric Nursing, 2002. (See Videos/CD ROM below)

Everyday Ethics: Resolving Dilemmas in Nursing Home Life, Rosalie A. Kane and Arthur L. Caplan, Editors. Springer Publishing, 1990.

He's 20, and at 93, She's His Oldest Friend, New York Times, N.R. Kleinfeld, May 14, 2003.

Quality of Life Measures for Nursing Home Residents, Kane, R.L.; Kling, K.C.; Bershadsky, B; Kane, R.L.; Giles, K.; Degenholz, H.B.; Liu, Jiexin; and Cutler, L.J. The Journal of Gerontology: Medical Sciences, Vol 58A, No. 3, 240-248, 2003.

Long Term Care and a Good Quality of life: Bringing them Closer Together, Kane, R.L., The Gerontologist, Vol 41, No. 3, 293-304, 2001.

Quality of Life in Nursing Homes From a Consumer Research Perspective, Gwen C. Uman, RN, PhD, Vital Research, Los Angeles, CA, Paper presented in July, 1996.

Evaluation of the LTC Survey Process, HCFA (now CMS), Chapter Five, “Quality of Life: Results from Resident Interviews and Observations.” Contact Karen Schoeneman, Project Officer, Centers for Medicare & Medicaid Services, 7500 Security Boulevard, Baltimore MD at 410-786-6855 or kschoeneman@hhs.cms.gov. This study was done by ABT Associates in 1994 and became the basis for the new survey procedures in quality of life.

Resident Council Handbook. A step by step guide to forming resident councils. Ideal for residents, facility staff, and ombudsmen. Created by and for residents. Contact Resident Councils of Washington @ www.residentcouncil.org

Videos and Game

Bathing without a Battle: Personal Care of Individuals with Dementia. A training video and CD ROM of Barrick, A; Rader, J; Hoeffer, B; and Sloane, P., Springer Series in Geriatric Nursing, 2002. Purchase at: www.bathingwithoutabattle.unc.edu for $30.

Making It Home: Residents’ Rights In Board And Care And Assisted Living. A 15 minute video with a self-instructional Study Guide. Colorado State Long-Term Care Ombudsman Program. The Legal Center, 455 Sherman Street, Suite 130, Denver, CO 80203. (800)288-1376.

Nursing Home Care Plans: Getting Good Care. A 16 minute video, leader’s guide, and handouts on individualized care planning and resident participation.1999, 2000. AARP, 601 E Street, NW, Washington, DC 20040. www.aarp.org

Residents Have the Answers: Improving the Quality of Life in Long-Term Care. A 33 minute video, a complete training and resource guide and PC computer diskette with questionnaire templates that can be customized for different facilities. Available from Terra Nova Films, Inc., (777)881-8491 or Lisa Zabar at Independent production fund (800)727-2470.

Residents’ Rights Bingo Game. A board game on the residents’ rights in nursing facilities. Can be used in many ways for teaching or reviewing with residents, facility personnel, or ombudsmen. Developed by Virginia Fraser when she was CO State Long-Term Care Ombudsman. To obtain contact the Colorado State Long-Term Care Ombudsman Program. The Legal Center, 455 Sherman Street, Suite 130, Denver, CO 80203. (800)288-1376.

Strength in Numbers: The Importance of Nursing Home Family Councils. A 20-minute video and leaders guide provide an overview of techniques and strategies for effective family council development. National Citizens’ Coalition for Nursing Home Reform, 1828 L Street, NW, Suite 801, Washington, DC 20036. (202)332-2275, www.nursinghomeaction.org

NCCNHR Publications

For more information, contact NCCNHR at 1828 L Street, NW, Suite 801, Washington, DC 20036, (202)332-2275 or www.nursinghomeaction.org

Residents' Rights Week packets include resources and ideas for year-round effective training. Easy to carry "kit" with room for state and facility specific information. Kit includes diskette with presentations, promotional items and training materials.

"24/7 Residents' Rights Around the Clock"- Residents' rights Week packet 2003

"Giving Voice to Quality: Affirming Residents' Rights in Long Term Care" Residents' Rights Week packet 2002

"Opening the Door: A Residents' Right to Visitation" Residents' Rights Week Packet 2001. Care Planning, 2005

Maryland Family Council Project, "Why Family-Led Family Councils Benefit Families, Residents, and Facility Personnel."

Consumer Fact Sheets related to residents' rights and quality of life- two-page free fact sheets:

Residents' Rights
Access and Visitation
Restraint Use
Involuntary Transfer and Discharge

MODULE V

COMMUNICATING EFFECTIVELY WITH OLDER ADULTS

MODULE V: COMMUNICATING EFFECTIVELY WITH	

Learning Objectives:

1. To learn and be able to use effective verbal and nonverbal communication techniques with older adults.

2. To use assertive communication effectively.

3. To be able to communicate effectively with hearing-impaired and vision-impaired older adults.

4. To communicate more effectively with the elderly who have aphasia.

5. To communicate more effectively with the elderly who have dementia.

6. To communicate better with the elderly who are unresponsive/withdrawn.

7. To communicate better care providers.

Module V: Communicating Effectively with Older Adults

OUTLINE

Introduction

For our purposes, "communication" refers to the person-to-person exchange of messages or information. Communication is usually more rich, varied and subtle than we realize. We will discuss a number of ways to communicate, as well as key factors that influence communication.

There are two basic types of communication.

1. **Verbal Communication** - Verbal communication simply refers to the words we use.

2. **Nonverbal Communication** - Nonverbal communication accounts for most of the information we communicate, and tends to convey our true emotions. Nonverbal communication includes:

Facial Expression

Facial expressions are responsible for a huge proportion of nonverbal communication. Consider how much information can be conveyed with a smile or a frown. While nonverbal communication and behavior can vary dramatically between cultures, the facial expressions for happiness, sadness, anger, and fear are similar throughout the world.

Gestures

Deliberate movements and signals are an important way to communicate meaning without words. Common gestures include waving, pointing, and using fingers to indicate number amounts. Other gestures are arbitrary and related to culture.

Paralinguistics

Paralinguistics refers to vocal communication that is separate from actual language. This includes factors such as tone of voice, loudness, inflection, and pitch. Consider the powerful effect that tone of voice can have on the meaning of a sentence. When said in a strong tone of voice, listeners might interpret approval and enthusiasm. The same words said in a hesitant tone of voice might convey disapproval and a lack of interest.

Body Language and Posture

Posture and movement can also convey a great deal on information. While these nonverbal behaviors can indicate feelings and attitudes, research suggests that body language is far more subtle and less definitive that previously believed.

Proxemics

People often refer to their need for “personal space,” which is also an important type of nonverbal communication. The amount of distance we need and the amount of space we perceive as belonging to us is influenced by a number of factors including social norms, situational factors, personality characteristics, and level of familiarity.

Eye Gaze

Looking, staring, and blinking can also be important nonverbal behaviors. When people encounter people or things that they like, the rate of blinking increases and pupils dilate. Looking at another person can indicate a range of emotions, including hostility, and interest.

Haptics

Communicating through touch is another important nonverbal behavior. There has been a substantial amount of research on the importance of touch in infancy and early childhood. Harry Harlow’s classic monkey study demonstrated how the deprivation of touch and contact impedes development. Baby monkeys raised by wire mothers experienced permanent deficits in behavior and social interaction.

Setting the Stage for Effective Communication: Create a Positive Atmosphere

1. Don't stereotype! Older people are individuals.
2. Don't talk down to an older adult. Don't treat him or her as a child.
3. Show genuine warmth, responsiveness, caring and a supportive attitude.
4. Demonstrate nonjudgmental acceptance of, and respect for the person. Remember that to accept a person is not the same as accepting or approving of that person's actions.
5. Be aware of feelings (the other person's, as well as your own). Indicate openness to any feeling or viewpoint by what you say and how you respond.[19] Remember that:
    - Feelings are neither good nor bad. They just are.
    - Feelings are not dangerous, although they can be painful. It is the behaviors chosen in response to a feeling that may be judged "right" or "wrong."
    - Everyone has a right to his or her own feelings. Feelings always make sense to a person in the context of his/her personal experience and frame of reference.
    - Denying a feeling (pretending not to feel it) will not make it go away. In fact, the feeling may grow or become more troublesome until it is faced.
6. Express empathy, not sympathy. Empathy is a deep awareness and sharing of another person's thoughts and feelings. Empathy involves "walking in another person's shoes," while remembering that each person is a separate, unique individual.
7. Give the person time to process information and respond.
8. Invite the other person to communicate.
    - Do not try to make him/her communicate.
    - Do not take over the conversation by dominating the topics or doing all or most of the talking. Empower the other person and let him/her control the pace of the conversation.

9. As necessary, introduce yourself, beginning interactions by:
    - Giving your name and your role.
    - Explaining why you are there, if this not clear to him/her.
    - Clarifying what will happen, if not clear.

    Do not ask the resident, "Do you remember my name?" or a similar question. That type of question puts the resident on the spot, elevates the resident's stress level, and calls upon the resident to utilize short term memory, which normally is more difficult to use as a person ages. [** Refer to exercise**]
10. Greet the resident by Mr., Mrs., Miss, or Dr., and family name unless the resident asks you to use another name.
11. Always knock on the door to a resident's room before entering, even if the resident can't verbally respond or if the resident is watching you approach. Knocking acknowledges that the room is their "space" and home. It also conveys a sense of respect for their privacy and dignity.
12. Ask the person for permission to talk or discuss a situation.
13. Be sure you allow time to socialize a little. Chat.
14. Choose an appropriate place for the type of conversation or visit you plan to have with the resident. If you are just greeting people, a day room or porch setting is appropriate if that is where the residents are sitting. If you need to discuss personal information, find a setting with privacy and quiet.

The setting in which communication occurs directly impacts the nature of the interaction.

15. Be dependable. Visit or check back when you said you would. Promise only what you can deliver/control.
16. Be honest. Avoid giving false hope or stating platitudes. It's OK to admit, "I don't know."
17. Cultivating friendly, trusting relationships takes time. Be patient in visiting. Allow residents to get to know you while you are learning about them. Rarely does a person divulge their innermost thoughts or problems until a trusting relationship has been established.

[1] Sources on feelings include:

- Ellis, A. (1977). **How to Live With - and Without - Anger**. New York: Crowell; pp. 13-15.
- Izard, C.E. (1971). **The Face of Emotion**. New York: Appleton-Century-Crofts.
- Neu, J. (1977). **Emotion, Thought and Therapy**. Los Angeles: University of California Press.
- Gaylin, W. (1979). Feelings: Our Vital Signs. New York: Harper and Row.

Exercise

Practice introducing yourself and explaining what the Ombudsman Program does. Try using an introduction that identifies your role, agency affiliation and that uses the term "Ombudsman." Many people are uncomfortable using the term "ombudsman" and never get around to mentioning it. However, educating the public about the program is a major part of the ombudsman role.

Let's look at an example of an introduction:

> Hello. My name is _____. I'm a Long Term Care Advocate with the Ombudsman Program. I volunteer with (Agency). The Ombudsman Program tries to help residents with any concerns about their life here in (care facility). I'll be visiting the residents here every week -- checking in to see how things are going for you, and answering any questions that I can.

- Have the class divide into groups of two (dyads).
- Each partner is to take a turn introducing himself and the Ombudsman Program.
- Discuss what was difficult and easier for the participants.

Guidelines for Effective Listening

1. Listening is a process of helpful communication. Be prepared to listen to the resident's real thoughts and feelings.

2. Your attitude should express that you value and accept the resident as an individual person.

3. The resident may present a problem that just seems to him/her that it cannot be resolved. Realize how upset he/she may be. Help the resident describe the problem and how and when it started, who is involved, etc.

4. The resident has the right and ability to make and take responsibility for his/her decisions. He/she may not want assistance at this time.

5. Be helpful and concerned, consistently treating the resident with dignity and respect.

6. Let the resident know that she/he is important and his/her concerns deserves attention, no matter how small it seems to you or to him/her.

7. Attempt to divide the problem into manageable areas. The resident may be feeling confused and overwhelmed. Help the resident get a handle on the problem areas.

8. Listen carefully for the resident's tone of voice and mood. What does the resident's tone tell you about his/her thoughts and feelings?

9. Respond in a way that lets the resident know that you are actively participating in the conversation. Some resident may be overwhelmed with thoughts and feelings about their problem. Let the resident know that you are hearing his/her concerns.

10. Find out how the resident has handled similar problems in the past. This will give you clues on what might or might not work this time.

11. No solution is right for everyone. Discuss different approaches to handling the problem.

12. Never raise false hopes or make false promises. Do not say, “Everything will be better soon”.

13. Be honest with the resident. Let the resident know if you do not have an answer readily available. Inform the resident that you will attempt to obtain information or refer he/she to an agency that can more adequately meet his/her needs.

14. End the conversation by summarizing the outcomes of the discussion. If necessary, help the resident develop a plan of action.

Listening for Clues:

As you listen to residents and observe their care, be very attentive and sensitive to what you see and hear. As an ombudsman, you are in a unique position to educate residents regarding their rights and the services to which they are entitled. You also have a responsibility to observe the overall care that the facility provides. To do this requires having good rapport with residents, using effective communication skills and remaining alert to clues you see and hear. Consider some examples of listening for clues that may point to an underlying problem/concern or for opportunities to provide information.

- In the course of a conversation, a resident says, "I used to complain about always having cold coffee, but I don't anymore. That's something I'll have to learn to live with. I guess I really shouldn't expect the service here to be like a restaurant."

As an ombudsman, you might ask: "What happened when you complained about having cold coffee?" This might be a time to explore the coffee service, the way the facility responds to complaints, and any underlying concerns the resident might have regarding the quality of services in general.

- As you visit, you notice that a resident seems unusually tired. She says that she was up most of the night, giving her bed-bound roommate water, calming her fears, and trying to get her to sleep. She says she doesn't know what would happen to her roommate if she didn't take care of her.

As an ombudsman, you could inquire about the nursing service at night, the resident's sense of responsibility for her roommate, the resident's desire to transfer to another room where she might get more sleep, and any underlying concerns the resident might have regarding the care she would receive if she were bed-bound.

If a resident tells you a story, listen carefully and try to determine why the resident chose this time to tell you. Is the resident merely sharing a bit more of herself with you? Is the resident trying to make a point? Is the resident trying to draw a parallel to some aspect of nursing facility life? Remember to solicit feedback before you reach any conclusions about the purpose of the story.

As an ombudsman, make a conscious effort to continually LISTEN and OBSERVE while you are inside the nursing facility. Even when a resident cannot express him/herself effectively, his/her behavior, circumstances and environment can be eloquent. Careful use of your observation skills can make the difference between problems being ignored and resolved. These skills take time, energy and practice, but they are vital to your effectiveness as an ombudsman.

Improve Your Verbal Communication

1. Think before you speak.

2. Use everyday words. No jargon.
   - Be careful of words that have different meanings for people from different backgrounds (e.g., "supper" in urban vs. rural areas). Any other examples?
   - Be careful of words or phrases with strong emotional content.

3. Use clear sentences.
   - Be sure your sentences are not too long. Limit use of conjunctions (e.g., "and," "but").
   - Be specific. Say what you mean. Get to the point.

4. Ask questions. Asking for additional information demonstrates that you are paying attention. If possible, use open-ended questions, which leave the response completely up to the other person ("How do you feel?"). While any form of seeking further information can show interest, open-ended questions are more effective at opening the door to further communication. In using open ended questions, ask "what" or "how," not "why." "Why" puts people on the defensive. It tends to press people to justify their thoughts, feelings or actions. "What" or "how" helps people focus on their experiences (e.g., "What happened just before you felt that way?", "How/what are you feeling?").

5. If the older person is upset, try putting the most important information at the end of a sentence.

6. If the person does not understand what you have said, repeat it once. If he still does not understand, try rephrasing using different words.

7. Do not ask a person to read or fill out a form and listen at the same time.

8. If a person responds with "I don't know":
    - Ask "What else?" or "What do you guess/think?" with an expectant expression.
    - Comment in a caring, positive way on how the conversation seems stuck.

9. Offer realistic reassurance, not phony support. ("No one will ever bother you again.")

10. As we have already discussed, listen for the content of the other person's communication (the factual meaning of the words) AND for the emotions being expressed.

11. Acknowledge that you heard the content and emotions. Remember, acknowledging what you have heard is not the same as agreeing with or supporting it.

Common Barriers to Communication

As we have discussed, communicating involves putting information into code, including our words, voice quality and body language. The other person then decides what the message means (i.e., decodes it). Communication can break down anywhere in this process of coding and decoding. Your response to a resident or staff member can erect a barrier to communication or it can open the door to understanding and trust. It can mean the difference in being effective as an ombudsman or being ineffective.

Some of the more common barriers to communication include:

1. **Not Listening.** If we don't turn on the radio, we can't receive the broadcast. Similarly, when we do not listen, we don't receive the message, so we can't decode it and respond appropriately. Glossing over information the resident shares with you, selectively hearing problem statements or "tuning out" completely are all forms of not listening.

   > If a resident says, "They don't treat me very well, but I'm managing to take it one day at a time", don't respond by saying "Yeah, well, that's the way it is sometimes" and then changing the subject.

   Another form of not listening to residents is letting the administrator or staff monopolize your time. This can erect a barrier to communication with residents by severely limiting the amount of time you have with the residents. It might also impair your effectiveness with residents if you are perceived as being too close to the facility personnel. Although cultivating a good working relationship with the administrator and staff is very important, you are in the facility to visit the residents.

   Nursing facility personnel can, either consciously or unconsciously, consume much of your time. Be sure your visits with personnel are purposeful, not just friendly chat sessions unrelated to your mission in that facility.

2. **Incorrectly Interpreting What Is Said.** People have "different code books" due to:
   - different family customs,
   - different life experiences,
   - different cultural groups.

   The ages of the people trying to communicate also may be a factor in misinterpretation. The physical, economic, social, cultural and psychological aspects of aging may affect communication between older adults and younger people. For example, American culture was much more formal when today's older adults were growing up than it is today. As a result, using an older person's first name on first meeting may be taken as an insult or, at least, as a sign of bad manners. What other examples have you seen of these causes of misunderstandings?

3. **Not Saying What Is Meant.** Sometimes we don't say what we really mean. Suppose I am tired at the end of a tough day and my child is chattering about something or wanting to play a game. In my tiredness, I might say "Stop being such a pest" instead of "I'm too tired right now. Let's talk in half an hour.

4. **Using Put-Down Messages.** In general, put-down messages shut down communication by portraying the speaker as superior and the listener as inferior. This implies that the speaker "has the power" and the listener is powerless or ineffectual. Put-down messages take many forms, including the following:
   - **Moralizing, Preaching** ("It's not right to say that.")
   - **Lecturing, Giving Logical Arguments** ("It doesn't make sense to feel that way.")
   - **Advising, Giving Solutions** ("What you should do is...")
   - **Judging, Criticizing, Blaming** ("It's your fault." "You're rude.")
   - **Interpreting, Diagnosing, Analyzing** ("You just want attention.")
   - **Sympathizing, Reassuring, Consoling** ("Poor baby.")

   Offering sympathy, false hope, phony reassurance or platitudes is devaluing, destructive and can block communication.

For example:

-When a resident says she hopes her doctor (son, daughter, etc.) comes soon, refrain from saying, "I'm sure he will." (Flippant reassurance.)

-If a resident tells you, "I hope I get over this problem soon; I don't know what I will do!", don't say, "I'm sure everything will work out fine." Also avoid statements like, "Don't think about things like that."

- **Probing, Interrogating (**Getting information so you can solve the person's problems for him/her.)

- **Withdrawing, Distracting, Humoring** ("Your problem reminds me of the joke about ...")

One of the more common forms of this barrier is changing the subject when the topic is uncomfortable for you. For example:

If a resident wants to talk about death and dying or about how much he misses his wife, don't change the subject because you find the topic morbid or depressing.

A resident may want to express her anger towards her daughter. Hearing this makes you uncomfortable because you know the daughter. Your role as an ombudsman is to listen and hear the resident's position. It is NOT your role to defend the daughter. If ever there is a case where you cannot maintain an objective perspective, refer the case to someone else and excuse yourself.

These responses shift the focus of the conversation away from the resident to you. As a result, you are not likely to pick up on what is important to the resident, and you may waste valuable time in the nursing facility.

Another form of this barrier may occur when a person does not want to take the time to discuss a problem or generally discounts what the resident is saying.

For example:

If a resident says, "I never get bathed and dressed in time for the morning craft class", a statement like, "I'm sure the nursing assistants work as fast as they can. This is a big facility and someone has to be at the end of the schedule" might impart a sense of futility to the resident.

Overall Guidelines for Effective Communication

It is more effective to:

1.	focus on behavior ("Talking")	instead of	1.	the type of person ("Chatterbox").
2.	focus on objectively describing behavior ("Yelling")	instead of	2.	judging behavior ("He's rude.").
3.	focus on the "here-and-now" ("You just interrupted me.")	instead of	3.	generalities; the history of the relationship ("You always do that.").
4.	accept responsibility for your reactions; "own" your problems ("I'm having a problem with you.")	instead of	4.	blaming your reactions and problems on others ("You made me upset.").
5.	focus on sharing and inviting the other person to share and help solve the problem ("What do you think?")	instead of	5.	giving advice; telling the other person what to do. ("You should..."; "You'd better...").
6.	mainly listen	instead of	6.	mainly talk.

Assertive Verbal and Non-Verbal Communication

Assertiveness is an attitude and a technique which allows a person to express views and stand up for rights without violating the rights of others. Assertiveness requires skillful use of both verbal and non-verbal communication techniques. It can be one of the most important skills you will use in your ombudsman work.

An ombudsman must represent a resident's interests in a strong, but sensitive manner. When making inquiries on behalf of a resident it is important that you gain the respect of those you deal with. It is also important that you express the needs and desires of the resident, without alienating others on whom the resident may depend for services.

Acting assertively will increase self respect and confidence. Some people may sometimes disapprove of assertive behavior. However, respect and admiration can be gained by being responsibly assertive, showing respect for self and others, having the courage to take a stand and dealing with conflict openly and fairly. Perhaps most importantly, assertion, more frequently than non-assertion, results in individuals getting their needs satisfied and preferences respected.

The process an advocate goes through to produce an assertive attitude looks something like this:

Validate the point of view of the other person. Acknowledge what the other person is saying and the point they are making.

2. **State your own problem, issues, or position.** Be very clear and concise in this description.
3. **State what you want.** Clearly define the result you want to obtain. Have in mind the minimum you will settle for but do not reveal that until necessary in negotiating.

The following chart compares assertive behavior with passive and aggressive behavior. The differences among these three types of communication are clear. By reviewing the chart you can see why assertiveness will be helpful in your advocacy work.

A COMPARISON OF PASSIVE, ASSERTIVE, AND AGGRESSIVE BEHAVIOR

ITEM	PASSIVE	ASSERTIVE	AGGRESSIVE
Behavioral Characteristics	Emotionally dishonest, indirect, self-denying, inhibited	(Appropriately) emotionally honest, direct, self-enhancing, expressive	Direct domineering at expense of another, cutting off communication, putting others down
Your feelings when you engage in this behavior	Hurt, anxious at the time and possibly angry later	Confident, self-respecting at the time and later	Righteous, superior, deprecatory at the time and possibly guilty later
The other person's feelings about her/himself when you engage in this behavior	Guilty or superior	Valued, respected	Hurt, humiliated
The other person's feelings toward you when you engage in this behavior	Irritation, pity	Generally respected	Angry, vengeful

Assertive Techniques

General Techniques: Assertiveness training is based on the idea that behavior is learned and thus can be unlearned. If we receive a positive response to a behavior, we are apt to repeat it. One way to strengthen our assertiveness skills is to begin with internal or self-reinforcement.

Verbal and Non-Verbal Language: Assertive communication must be clear, easily understood and direct. Assertiveness requires that your non-verbal communication be consistent with your verbal communication. For example, body language can be passive, aggressive or assertive.

Passive Body Language: Giggling, eyes cast down, shoulders slumped, wringing hands in despair, shrugging shoulders.

Aggressive Body Language: Waving a finger in warning, a sneering expression, shaking your head in disapproval, looking down your nose, leaning forward, standing/sitting very close, making fists.

Assertive Body Language: Standing/sitting erect but comfortable, attentive, confident expression and relaxed yet forceful.

Assertive body language is an essential part of assertive communication, as is voice quality. For instance, assertiveness is communicated by speaking in a voice that is steady, with a confident tone, moderate speed and volume that projects without being too loud.

Verbal communication also plays a part in assertiveness. The words we use can be passive, aggressive and assertive.

Passive Words include "How did I do?," "Do you think I did that all right?," "Help me," "I can't ...," "I'm sorry, but I...," "I don't know," and other discounting words and phrases.

Aggressive Words include "should," "must," "have to," "insist," "honey," "cutie," threatening words and put-downs.

Assertive Words are generally questioning words and phrases such as "who," "what," "where," "how," "when;" "Let's work this out," "Let's think about it." Using cooperative words and neutral language. "I-messages," which we already have discussed, are a particularly important form of assertive verbal communication.

Overall, body language, voice quality and our words all contribute to the effectiveness of assertive communication.

Resisting Interruptions: Sometimes, it can be especially important to complete what you want to say without interruption. There are several approaches which can help. Try each of them until you find the approaches which are most comfortable for you:

1. Raise your voice and keep on talking. The interrupter may stop.
2. Repeat your opening phrase. (I think, well, I think...)
3. Pause for a second, and then quickly continue what you were saying.
4. Use body language. Lean in toward the person with whom you were speaking and don't look at the interrupter. Signal with a raised hand for him/her to stop, while you continue.
5. Stop talking. Look at the interrupter and say, "I'm talking. Give me a few seconds to finish." Begin talking again.
6. Don't apologize to the interrupter. Make eye contact and continue talking.

Methods of Being Assertive: There are several ways in which we can be assertive, including simple assertion, empathic assertion, pointing out discrepancies, escalation of assertions, broken record and sidestepping.

Simple Assertion -

- A statement of fact
- Refers to yourself or your wishes
- Appropriate, not rude

Empathic Assertion -

- Gives recognition and appreciation of the feelings or position of the other person, without giving up your own
- Shows respect, concern, and mutuality of goals
- Combines sensitivity and firmness
- Allows the speaker to understand the other person's point of view, thus keeping perspective and reducing the possibility of overreacting

Pointing Out Discrepancies -

- Focus on the behavior (not the motives) of the other person
- Point out discrepancies between what was promised, and what was done; what was said before and now; what was agreed upon, but not carried out
- Pointing out a problem without accusing another

Escalation of Assertions -

- Starts out with the minimum forcefulness necessary to get your point of view across. If your rights are still not being respected, the firmness is increased, and the tone of voice becomes more action-oriented

Broken Record -

- Calmly repeat what you want, while validating the feelings of the other.

Sidestepping -

- Acknowledge the possibility that the other person has a valid (though irrelevant) point, while continuing to assert your point and advancing the conversation rather than stalling it. This allows the speaker to avoid becoming defensive by sidestepping criticism.

Special Issues in Communicating With the Hearing and Visually Impaired Elderly

Another area of special concern is communicating with older persons who have hearing and/or visual impairments.

Some Principles of Sensory Loss in Old Age

- All five senses tend to decline gradually throughout adulthood.
- It is more difficult to cope with multiple losses than a single loss.
- People consciously and unconsciously develop ways to compensate for sensory losses.
- The type and degree of sensory loss varies between individuals.
- To be more effective, know and respond to a person's sensory abilities and limitations.
- Don't be over-protective. A person with impairments should do as much as possible for himself/herself.
- Communicate directly with a person who has hearing or visual impairments, not through his/her companion.

Indicators of Hearing and Visual Impairment
Persons who have hearing loss are likely to exhibit some or all of the following behaviors.

- Leaning closer to the speaker.
- Cupping an ear.
- Speaking in a loud voice.
- Not speaking clearly.
- Turning his or her "good" ear toward you.
- Asking for things to be repeated.
- Answering questions inappropriately.
- Blank looks.
- Inattentiveness or signs of losing interest.
- Isolation or refusing to engage in conversation.
- Lack of reaction.
- Emotional upset -- perhaps anger.

Visual changes vary even more between older people than hearing changes. Elderly persons who have vision problems may exhibit some of the same behaviors as those with hearing loss. They may also:

- Squint, frown or grimace during conversation.
- Rely more on touching.
- Give inaccurate descriptions of detail or colors.
- Lack eye contact.
- Appear to be distrusting and/or withdrawn.
- Seem to be worried about awkwardness.
- Exhibit a reluctance to communicate.
- Appear to be fearful of even normal activity.

Communicating More Effectively with the Elderly Who Have Hearing and/or Visually Impairments

Techniques for communicating more effectively with an elderly person who has hearing and/or visual impairments include the following:

- Be sure that the individual is aware of your approach and that you have the older person's attention before speaking. Be careful not to startle the person.
- Position yourself directly in front of the person when you converse. Adjust your distance from the person depending on the person's visual, hearing and cultural/personal needs.
- Face the person and do not chew gum, smoke, turn away or cover your mouth.
- If possible, position yourself so that there is a plain background behind you (e.g., a plain wall instead of a bookcase).
- Allow extra time to converse. Slow down yet speak at a natural pace. Give plenty of time for the person to respond. Trying to rush will compound everyone’s stress and create barriers to having a meaningful conversation.
- Tell the person if you move around or leave the room.
- Pronounce your words clearly. Don't mumble, yet do not exaggerate words or sounds. Don't speak one word at a time.
- Use simpler, shorter sentences to make your conversation easier to understand.
- Lower the pitch of your voice. If you have to raise the volume of your speech, do not shout or raise the pitch of your voice. Sometimes try lowering the pitch of your voice instead of increasing your volume.
- Use gestures and objects to clarify what you are saying. For example, you might point to your eyes for "See" or point to your mouth for "Eat."
- A touch on the hand may aid in concentration, thus improving comprehension.

- Limit background noise and distractions (e.g., TV, radio, fan, and people).
  Be especially careful that lighting is appropriate.
  - Arrange for a higher than usual level of light from several, non-glare sources.
  - Be sure that lighting is glare-free and shadow-free.
  - Be certain that lights and windows are behind the elderly person, rather than behind you so that your face is not in shadow.
- Have a pen and pad of paper available. If necessary, print your message. (Be sure that the person can read the language in which you print.)
- Recognize that people with hearing and vision impairments often understand less well when they are tired or ill.
- If a person has difficulty understanding something, find a different way of saying it, rather than repeating the original words over and over.

Additional Guidelines for Communicating Effectively with the Elderly Who Have Hearing Impairment

- Find out if the resident has ever worn a hearing aid. If the resident has and the hearing aid isn't visible, find out if it is in the resident's room, at the nurses' desk, or somewhere else. Ask why the resident isn't wearing the hearing aid.
  - If the person wears a hearing aid and still has difficulty hearing, check to see if the hearing aid is in the person's ear. Also check to see if it is turned on, adjusted, and has a working battery. If these things seem to be fine and the resident still has difficulty hearing, find out when the resident last had a hearing evaluation.
  - You may need to speak to the individual's "good" ear.

Additional Guidelines for Communicating Effectively with a Deaf Older Adult

Communicating with residents who are deaf is similar to communicating with the hearing impaired.

- Ask staff how they communicate with the deaf resident.
- Write messages if the resident can read.
- Use a picture gram grid or other device with illustrations to facilitate communication.
- Be concise with your statements and questions.
- Utilize as many other methods of communication as possible to convey your message.
- Allow sufficient time to visit with the resident without having to be rushed or under pressure.

Additional Guidelines for Communicating Effectively
with the Elderly Who Have Visual Impairment

- Use whatever vision remains.
- Ask how you may help.
- Check if the person's glasses are clean.
- Allow the person to touch you.
- If you are entering a room with someone who is visually impaired, ask if he/she wants you to describe the room layout, other people who are in the room, and what is happening.
- Tell the person if you are leaving the room. Let her know if others will remain in the room or if she will be alone.
- Explain what you are doing as you are doing it, for example: taking notes, looking for something, putting the wheelchair away.
- Say the person's name before touching. Remember that touching lets a person know you are listening.
- When you speak, make clear whom you are addressing.
- Use the words "see" and "look" normally.
- When you are in a visually impaired person's room or home, leave things where he or she has placed them so they can be easily found later.
- Legal blindness is not necessarily total blindness. Use large movement, wide gestures and contrasting colors.
- Use large, clear lettering in any written material.
- Encourage independence as much as possible.
- Treat him/her like a sighted person as much as possible.

Special Guidelines for Communicating with the Elderly Who Have Aphasia

Aphasia is a total or partial loss of the power to use or understand words. It is often the result of a stroke or other brain damage. People with expressive aphasia can understand what you say, but people with receptive aphasia cannot understand. For persons with expressive aphasia, trying to speak is like having a word "on the tip of your tongue" and not being able to call it forth. Some persons may have a bit of both kinds of impediment. Some suggestions for communicating with individuals who have aphasia follow.

- Ask the person and the staff how best to communicate. What techniques or devices can be used to aid communication?
- Be patient and allow plenty of time to communicate.
- Allow the individual to try to complete her thoughts, to struggle with words. Avoid being too quick to guess what the person is trying to express.
- Be honest with the individual. Let her know if you can't quite understand what she is telling you.
- Encourage the person to write the word he is trying to express and read it aloud.
- Use gestures or point to objects if helpful in supplying words or in adding meaning.
- A picture gram grid is sometimes used. These are useful for "fill-in" answers to requests such as, "I need" or "I want". The resident merely points to the appropriate picture.
- Use touch to aid in concentration, to establish another avenue of communication, and to offer reassurance and encouragement.

Special Guidelines for Communicating with the Elderly Who Have Alzheimer's Disease or Other Dementias

There are many suggestions for talking with someone who has Alzheimer's disease or other dementia. A few of these tips are:

- Always approach the individual from the front, or within his or her line of vision, no surprise appearances.
- Speak in a normal tone of voice and greet the person as you would anyone else.
- Minimize your hand movements.
- Avoid a setting with a lot of sensory stimulation, like a big room where many people are sitting and talking, a high traffic area, or a very noisy place.
- Be respectful of the person's personal space and observant of his/her reaction as you move closer.
- If the person is walking, walk with her, in step with her pace while you talk.
- Use distraction if a situation looks like it might get out of hand. A couple of examples are: if a resident appears about to hit someone or if a resident seems to be going outside of the nursing facility grounds.
- Allow ample time for the person to respond to conversation.
- Ask a question when something is unclear.
- Give clues to reality (e.g., "I am ____ and I've come to visit you" or "It is so cloudy and dark this morning that it seems like evening").
- When an individual has impairment in mental functioning, it is appropriate to respond to that person's feelings even if his/her statements do not make sense to you in the context of your conversation.

An example is a woman who says her daughter is coming to visit her today. A visitor may know that the daughter is not coming and respond by saying, "You must miss your daughter and are anxious to see her." That response allows the woman an opportunity to discuss the relationship or her feelings, but it does not reinforce the false expectation that the daughter will come that day.

- Before assuming that a person is mentally confused or out of touch with reality, it is important to ask questions. By asking questions like, "What do you mean?" "What were you thinking about before I came?" or "What did you hear?" the visitor may better understand the individual's statements. What had previously seemed confused may make sense once a complete explanation is obtained.
- Be aware of your voice tones and be sure to keep them on an adult level.

Special Guidelines for Communicating with the Elderly Who Are Unresponsive or Withdrawn

Communicating with unresponsive or withdrawn residents is often difficult for most people because you receive no feedback. You don't know if your message has been received or what the other person's reaction to it is. Non-responsive residents mean individuals who seem incapable of giving a verbal or nonverbal response. These may be residents:

- who are comatose;
- who are withdrawn and don't acknowledge your presence;
- who are apparently completely in a world of their own, or
- for whom no effective method of communication has been found.

Sometimes non-responsive residents have shocked their visitors by saying a few words or by giving a clear response after weeks of no obvious response. Although there is no one, correct way to visit with these residents, there are a few tips to remember.

- *Be sure to visit non-responsive residents*. If a resident is difficult for you to visit, other people may not visit that resident either for the same reasons you have difficulty. These residents are often the least visited, and thus receive the least stimulation, of all the resident population. They may therefore be among those individuals most in need of a visit.
- *Be present for the resident whenever you are in the facility.* If possible, hold the resident's hand or give a pat on the arm while verbally introducing yourself.
- *The visit may be short.* You may only state your name, the purpose of your visit, and stay for a few minutes of silent companionship.
- *While visiting the resident, observe the resident's appearance.* What kind of care does it seem the resident is receiving? Do you notice any changes in the resident's appearance from one visit to the next?
- *If appropriate, try different kinds of sensory stimulation as well as different conversational topics to see if something "strikes a chord" of responsiveness in the resident. You might try music, a feather, a carpet square, or a bright picture.*
- *Ask the staff what techniques they use to communicate with the resident.* Observe their interactions with the resident.

Special Guidelines for Communicating with Care Providers

Although much of an ombudsman's work is spent communicating with residents of nursing facilities, an ombudsman also needs to communicate effectively with care providers. When communicating with care providers remember the tips that follow.

- Clearly explain the nature of your role: why you are there, what you'll be doing, what they can expect from you, being careful to maintain confidentiality.
- Be sure to acknowledge the good work that providers do.
- Remember that care providers are very busy. Be respectful of the demands on their time. Be concise with your communication.

Summary

As an ombudsman, your visits are to be purposeful, with the resident as the focus. Although residents will hopefully be at ease with you, you are there to be an advocate. You have knowledge, training and skills to utilize on behalf of residents. Your communication skills can greatly facilitate that work.

Module VI

THE PROBLEM-SOLVING PROCESS
INVESTIGATION

Curriculum Resource Material for Local Long-Term Care Ombudsmen

Developed by Sara S. Hunt, Consultant

National Long-Term Care Ombudsman Resource Center
National Citizens' Coalition for Nursing Home Reform
1828 L Street, NW, Suite 801
Washington, DC 20036
Telephone: (202) 332-2275
Fax: (202) 332-2949
Email:
Web Site: www.ltcombudsman.org

APRIL 2006

ACKNOWLEDGMENTS

Many thanks to the Advisory Committee for the Local Long-Term Care Ombudsman Curriculum—Esther Houser, Oklahoma State Long-Term Care Ombudsman (SLTCO); Linda Sadden, Louisiana SLTCO; Eileen Bennett, Long-Term Care Ombudsman Program (LTCOP) Specialist, and Vivian Omagbemi, LTCOP Program Manager, Montgomery County, Maryland; Louise Ryan, Assistant Washington SLTCO, and Sherry Culp, Nursing Home Ombudsman Agency of the Bluegrass, Lexington, Kentucky, for their review, testing, and comments.

ABOUT THE AUTHOR

Sara Hunt, MSSW, is a consultant for the National Long-Term Care Ombudsman Resource Center with expertise in the areas of ombudsman training, policy development, program management, and care planning and quality of life. Sara was the State Long-Term Care Ombudsman in Louisiana for five years (1981-1986) and has served as a consultant to the Ombudsman Resource Center since 1987. For more than twenty-five years Sara has been developing and conducting training programs, most of those for ombudsmen. She is co-author of *Nursing Homes: Getting Good Care There.*

ABOUT THE PAPER

This curriculum module was supported, in part, by a grant, No. 90AM2690, from the Administration on Aging, Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

Module VI: Problem Solving

OUTLINE

INTRODUCTION[1]

The first function of a Long-Term Care Ombudsman Program (LTCOP) listed in the federal Older Americans Act is to:

Identify, investigate, and resolve complaints that are made by, or on behalf of, residents…[2]

This module focuses on the investigation process and skills used by Long-Term Care Ombudsmen (LTCO). Investigation is the foundation of resolving problems. Another module, "The Problem-Solving Process: Resolution," discusses the process and skills LTCO use to implement necessary changes after an investigation.

As a LTCO how you approach identifying, investigating, and resolving complaints directly affects:

- Your relationship with residents and staff,
- Your ability to achieve the desired outcome,
- Future relationship with residents, families, and staff, and
- The reputation of the LTCOP.

[1] Much of this module content is adapted from the *Long-Term Care Ombudsman Program Manuals* from Louisiana and Alaska, developed by Sara S. Hunt. Alaska manual available on www.ltcombudsman.org

2 Older Americans Act, § 712(a)(3)(A)(i).

OMBUDSMAN APPROACH TO PROBLEM SOLVING

In an institutional setting, certain practices and methods of operation are developed to ensure efficiency. While efficiency is a legitimate business concern, these practices and methods may conflict with the needs of individual residents. It has been argued that a "good facility" is one that attempts to balance the need for efficiency with quality of life issues; a "bad facility" is more likely to focus solely on efficiency.[3] Moreover, nursing homes are based on the medical model with its emphasis on health and safety concerns. These concerns sometimes overshadow the right to make choices that involve at least some degree of risk: an example is the use of restraints.

Problem solving or complaint resolution, is the primary means that ombudsmen use to ensure that residents' rights are understood and honored in such an environment. It involves educating residents, staff and others about rights, and helping to find practical solutions to problems that arise when the interests of the facility and the interests of the individual conflict.

Responding to and resolving complaints can be difficult. There will be times when you will be called upon to support the resident in a decision that may be clearly harmful to him/her. There will also be times when you will be trying to balance the rights of one resident against the rights of another. After all, in any communal setting, there will be differences of opinion and preference.

Whatever the situation, the process for approaching it is the same. Complaint handling is really nothing more than a problem-solving process. It is a systematic, rational process you follow, from receipt of a complaint through investigation and resolution. As you handle more and more complaints, you will adapt this process to your own style. Eventually, it will become second nature.

3 Wayne Nelson, Ph.D., Deputy Director, Oregon Ombudsman Program. "What Kind of Ombudsman Are You?" Speech delivered at the 13th Annual Louisiana Ombudsman Conference.

Uniqueness of the Ombudsman Approach[4]

The LTCO's goal in problem solving is achieving satisfaction for residents. The approach an ombudsman uses is critical not only to the immediate outcome but also to effectiveness in the future with residents and staff. If residents see ombudsmen working to build relationships, residents are better able to trust ombudsmen to help them without feeling that their own relationship with staff will be strained. Therefore, as an ombudsman, you must carefully select your strategies and be skillful and thoughtful in investigating and resolving problems. This resource module is designed to assist you in understanding the process and in refining your skills.

Real problem solving requires taking the time to understand what factors affect how the staff is working, as well as what the resident is experiencing. Since the LTCO's primary responsibility is problem solving, you can take the time to get to know the resident's situation in depth and to look into creative solutions that are workable for the staff and residents. A solution will work only if it is based on mutual understanding and if it works for all parties.

Ombudsmen seek to work in such a way that staff understand more of what is at the heart of a resident's concerns and find ways to respond to the resident's needs. As a result, ombudsmen hope to see a difference in the way care is provided for an individual in both observable aspects and attitudinal aspects. Working on behalf of one resident can lead to changes in facility policies and routine practices. Thus, all residents benefit.

The ultimate goal of the ombudsman approach to problem solving is to help staff become more responsive to residents and residents better equipped to directly express their concerns to staff.

[4] Adapted from "Ombudsmen as Problem Solvers" by Barbara Frank, in the *Training and Resource Manual for Volunteer Resident Advocates*. Connecticut Nursing Home Ombudsman Program. 1996.

Common Problems

Common problems likely to surface in facilities include:

Loneliness, the need for someone to talk with	Inability to live independently coupled with a desire on resident's part to leave facility
Boredom: not enough social or personal activities	Use, accounting, and safe-keeping of personal funds and personal possessions
Problem with roommate(s)	Limited opportunities to go outside the facility for community activities
Lack of privacy	Need for assistance to find or purchase services
Poor food service or quality	Insufficient medical or nursing care
Inability to get services, care, or attention because of physical or communication problems	Physical or mental abuse
Physical or chemical restraints	Additional or high charges for "extra" services
Neglect	No rehabilitative care
Transfer from one room to another without notice	Guardianship issues
Transfer to another facility because of change from private pay to Medicaid	Loss of dignity and self-respect based on general treatment in the facility
Need for assistance to document or make complaints	Need for legal assistance to make will or to make arrangements for disposing of personal funds or possessions, or for other matters

Barriers to Self-Advocacy

Residents may be unable to express their particular needs without assistance from others. Barriers to self-advocacy are manifold. There are at least three kinds of barrier to self-advocacy, as indicated below. They are physical and mental barriers, psychological/psychosocial barriers, and information barriers.

Psychological/Psychosocial
Fear of retaliation
Sense of isolation
Lethargy
Disorientation

Loss of confidence
Depersonalization
Disdain for the label complainer
Social pressure to conform
Fear of upsetting the family
Belief that this is the best it can be
Sense of hopelessness and/or despair
Inability to question authority
Mystique about medical issues
Lack of familiarity with staff
Lack of experience with assertive behavior, particularly for women
Stereotypes, fears about age
Sense of weakness resulting from illness

Physical and Mental
Hearing loss
Loss of speech
Immobility
Memory loss or other impairments in cognitive functioning
Inaccessibility of staff
Impaired vision
Diminished physical strength
Effects of medications
Depression

Information
The residents lacks information concerning:
Rights, entitlements, benefits
Authority with the facility
Legal and administrative remedies

Alternatives
How to improve the situation
The right to complain and how to advocate for change

Role of the Ombudsman/Advocate

As an ombudsman, you will be an advocate acting on behalf of residents. In some cases, you will be able to educate, support, and encourage resident to engage in self-advocacy, to represent themselves. In other situations, you will be representing the resident. Resident empowerment needs to infuse your problem solving. There are some basic guidelines to remember in advocacy. These "do's and don'ts" are listed below in Tables 1 and 2.

Another important aspect of the role of advocate is personal style, or demeanor, in presenting problems to staff. An approach that is hostile, aggressive (rather than assertive) or blaming will cause great damage to your working relationship and make it difficult for you to collaborate with the facility staff in solving problems. On the other hand, a style that is too passive will not be effective in ensuring that the resident's rights are respected.

As an advocate, you are called upon to be respectful, and sometimes even empathetic, to the concerns of the facility. Yet you must also be persistent and professional in your pursuit of the implementation of resident's rights. You can service the resident's interests best if your manner is "firm, fair, and friendly."[5]

Table 1: The Do's of Advocacy	Table 2: The Don'ts of Advocacy
• Respect the confidentiality of all complaints made to you. • Be a good listener. • Assure the resident that you are there to listen to his/her problem. • Speak clearly and slowly so that the resident can understand you. • Talk to the resident in a quiet, private area. • Explain things in a few words, rather than in long paragraphs, acronyms and jargon. • Be objective, yet understanding. • Give an accurate picture to the resident of what he/she can expect. • Convey a sense of care and desire to help the resident. • Remember that some residents may distort or exaggerate; therefore, an accurate and reliable assessment of the problem is necessary. • Work with the resident, the staff, and the administration in solving problems. • Remember that it may take some questions and perseverance to get to the real problem. • Make an effort to understand the total situation or problem by seeking out as many sources of information as possible. • Remember that the resident may tire easily, have a short attention span, digress during conversations, or simply become confused. • Keep accurate records as requested for the program.	• Do not provide physical or nursing care. This is the responsibility of the staff working in the facility and is for the resident's protection as well as the advocate's. • Do not bring unauthorized articles into the home such as food, drugs, prescriptions, tobacco, alcoholic beverages, or matches. • Never treat the residents as children. They have a lifetime of experience. • Do not diagnose or prescribe for a resident. • Do not make promises that may be impossible to keep. • Do not advise residents on business or legal matters; refer them to appropriate professionals. • Do not be critical of the residents or the facility. • Do not engage in arguments, but rather, stick to the question or problem at hand. • Do not forget that you are not an inspector of the facility. You are there to listen to individual complaints and try to resolve them.

[5] Wayne Nelson, Ph.D., Deputy Director, Oregon Ombudsman Program. "What Kind of Ombudsman Are You?" Speech delivered at the 13th Annual Louisiana Ombudsman Conference.

POLICY CONSIDERATIONS

Documentation

Documentation is extremely important for accurate reporting and for allowing others who may later become involved in a complaint to know what steps you've already taken. Furthermore, any complaint may at some time become a source of litigation, and clear documentation will be critical.

Some ombudsmen find keeping a diary or journal of their visits helpful. This allows them to remember personal information about residents, observations of potential problems, and events that may not seem significant at the time, but turn out to be important later. It may also make it easier to complete whatever forms the State Long-Term Care Ombudsman (SLTCO) requires for reporting on your activities. Be sure that whatever type of documentation you keep is consistent with the policies of your SLTCOP.

Confidentiality

All records and information obtained during an investigation or during the resolution process must be held in confidence. Information may only be disclosed if the complainant or resident or his/her legal representative consents to the release of the information or by court order.

Explain the confidentiality policy to the complainant at the outset of the complaint-handling process. Unless explicitly given approval to reveal someone's name, you must keep the name and identity of a resident or complainant confidential. In cases where complainants do agree to have their names revealed, you must document that permission was given at the time it was given. In cases where permission to act might become an issue, it is preferable to have a signed waiver of confidentiality. Signed waivers are also recommended, if not required, when the complainant's identity is revealed outside of the facility. Check with your LTCOP supervisor or the SLTCO for copies of these forms.

Permission to disclose the identity also applies to asking complainants other than the resident for permission to tell the resident that they contacted you. You need to ask, "Is it okay to tell Mrs. Jones that you contacted me about this problem?" You will usually be told "Yes." The section on ethical dilemmas offers guidance on how to proceed if you are told "No."

Sometimes people will make a complaint only under the condition of anonymity. If an individual insists on having his/her name kept secret, explain that, while you will do everything possible to protect their identity, there is the possibility that the facility may be able to determine who made a complaint. Explain that some complaints are virtually impossible to investigate without revealing the identity of the resident. For example, a complaint regarding a resident's finances may not be adequately checked unless financial records are reviewed, which would immediately indicate who had filed a complaint.

If the use of a complainant's name is initially denied but is needed to proceed further with a complaint investigation, talk with the person again to:

- explain the situation,
- request to use the complainant's name, and
- discuss any potential risks involved in the complainant being identified.

See Table 3 for additional guidance on this issue.

Encouraging Self-Advocacy

You should encourage the complainant to act on his/her own behalf. This is especially true if the complainant is the resident. Offer information, support, and guidance, but encourage the complainant to take action to resolve the problem. Sometimes a complainant may be willing to participate in the problem-solving process if you can be joined in any meetings to offer assistance. A more complete discussion of encouraging self-advocacy, empowerment, can be found in the module, Residents' Rights. If the complainant is not the resident, it may be necessary to ask the complainant if they have determined what the resident wants in the matter.

If the resident prefers that you act on their behalf, remember that you can do no more than what the resident gives you approval to do. You must also report back to the resident on your progress.

Sometimes a resident will insist that nothing be said or done. In such cases, you have no choice but to continue to check back with the resident to see if he or she wishes to proceed at a later date.

Alternatively, you might find other residents with the same issue who are willing to pursue it to resolution. By resolving the issue for others, you might be able to resolve it for the resident who does not want you to proceed on her behalf.

DILEMMAS IN RECEIVING COMPLAINTS

You will inevitably find yourself in a number of complaint situations that pose ethical dilemmas or call for special handling. The key to knowing how to respond to many of these situations is to remember that you represent the resident. Table 3 lists seven typical situations that may occur and gives suggestions for dealing with these dilemmas.

Table 3. Typical dilemmas and suggested responses.

Dilemma	Suggested Response
A family member complains about a resident's care, but the resident says everything is fine and asks you not to proceed.	*Your primary responsibility is to the resident*. If pursuing the investigation would identify the resident, you must discontinue it unless the resident grants permission to proceed. As an alternative, if you feel there is a problem with the care in the facility, you might be able to pursue a more general investigation, taking care not to do anything that would reveal the resident's identity.
The resident complains, but a family member urges you "not to rock the boat."	This case is more clear-cut: the resident has requested assistance, and you should honor that request. Explain to the family that you are obligated to assist residents in resolving problems.
Relatives want you to investigate their complaint, but do not want the resident to know what you are doing. (For example: two relatives are involved in a dispute over who is to provide for the resident's expenses; or, relatives may fear that the resident will be upset or alarmed by a problem.)	This is a particularly sensitive situation. It may be advisable to have a general conversation with the resident to ascertain whether he/she is concerned about the problem mentioned by the complainant. You will have to judge whether there is a problem concerning the resident. If the resident is being victimized, you are responsible for addressing the problem. You should not become involved, however, in family disputes, which are not affecting the resident's well being.
A resident who is unable to make decisions for him/herself, but has not been legally declared incapacitated, makes a complaint.	Even though the resident may be confused or unable to express a decision, you should check into his/her complaint. It cannot be dismissed as invalid just because it comes from someone who is confused. However the resident's condition should be considered as one factor in determining whether the complaint is valid. Consider what you know about the resident and about the facility. Try to

	understand what the resident is expressing; determine if there is an underlying message or unmet need.
A case arises involving a resident for whom a guardian has been appointed.	In most cases, you work through the guardian. Exceptions to this rule would be:
The complaint is about the issue of whether the guardian is needed.	• The guardianship is a limited one (the resident retains the right to make some decisions).
The interest of one resident runs counter to the well-being of a group of residents. (For example: a resident may complain about being denied the right to smoke, but others say that the resident has almost set the facility on fire by smoking in non-smoking areas.)	In such cases, try to determine the facts and help the parties arrive at a solution that, as far as possible, protects the rights of the individual and the group. Your role is to assist in addressing the rights of all residents, not upholding one resident's rights to the detriment of other residents.
A resident will not give you permission to reveal her identity but wants your assistance.	Discuss the reasons the resident does not want her identity revealed. If this will limit your ability to resolve the issue, discuss this with the resident and tell her you will do as much as possible without revealing her identity. If you cannot resolve the issue without revealing her identity, tell her what you've done and why you cannot take the case further. If appropriate, encourage the resident to discuss her concern with the Residents' Council. • Look for supporting evidence during your regular visits. • Look for supporting evidence when visiting other residents; perhaps several other residents share the same issue and you can proceed on their behalf. • Inform the resident that you will be available to pursue this issue if she changes her mind. Check back with her regarding this.
A complainant, other than a resident, insists on remaining anonymous and will not give you any identifying information.	As in the case of residents who do not wish their names used, such persons should not be forced to reveal their identity. The complaint, if specific enough, can be investigated using these techniques: • Look for supporting evidence during your regular visits. • Engage in casual conversations to see how residents feel about the issue.

	• Review recent complaints/survey reports to see if similar problems have been noted. • If all else fails, file the complaint for future reference in case similar problems arise.

USING THE THREE STAGES OF PROBLEM SOLVING

The problem-solving process includes three major stages of action, as indicated in Table 4. The stages are the following: Stage 1, Intake and Investigation; Stage 2, Analysis and Planning; and Stage 3, Resolution and Follow-Up. The first stage is discussed at length in the following narrative. Stage 2 and Stage 3 are discussed in the module, "The Problem Solving Process: Resolution." The stages are simply a way of organizing your work as you seek to resolve problems. If you ever wonder what to do next, consult Table 4, the narrative discussion of each stage in the modules, and Guidelines for Practice in the appendix, to check your work and get additional ideas.

Table 4. Stages in the problem-solving process.

Stage 1 Intake and Investigation	
Receive the Complaint	Receive problem, complaints, concerns.
Gather Information	Collect information from interviews, records, observations.
Verify the Problem	Review information gathered. Assess what seems to be at the root of the problem. The complaint may be only a symptom.
Stage 2 Analysis and Planning	
Analyze the Situation	Once you identify the problem, consider the causes.
Consider Solutions	Generate alternative solutions or approaches. Who should be involved? When? How? Why?
Identify Obstacles	Anticipate obstacles o help select an appropriate approach.
Stage 3 Resolution and Follow Up	
Choose an Approach	From your list of alternative solutions, choose the most efficient way to proceed, keeping any obstacles in mind. Identify alternative strategies in case you need them.
Act	Proceed with the selected plan, but be prepared to use an alternative.
Evaluate Outcome	Check back with the persons involved to evaluate outcomes. Is the problem solved? Is it partially solved? If not, look for new approaches or information and start again.

To understand how this problem-solving process applies to a LTCO case, take a look at an example. Use the following case as an individual study exercise to focus on the Intake and Investigation steps. White space is included for you to jot ideas and questions. If you work through each step, reading and understanding the remaining information in this module will be easier. You will be on your way to approaching situations as an ombudsman.

Example: Mrs. Bronner's Purse

As a LTCO you are visiting residents in Peaceful Acres Nursing Facility. When you stop in Mrs. Bronner's room, she whispers in an angry voice, "My purse is missing!"

What are some potential reasons that Mrs. Bronner says her purse is missing?

- She can't remember where she put it.
- Her daughter took it to have the strap repaired.
- Another resident wandered into the room and picked up the purse.
- Someone stole it.
- She never had a purse in Peaceful Acres.
- The purse is behind the bed where Mrs. Bronner can't see it.
- What Mrs. Bronner really wants is the special handkerchief her husband gave her that she always kept in her purse.
- Mrs. Bronner's purse is in her room but she is remembering a favorite purse she had many years ago.
- She left her purse in the dining room, and it is now in the box of "lost and found" items in the facility.

Because there are so many possible explanations for Mrs. Bronner's statement, how would you determine why Mrs. Bronner said her purse is missing? List a few ideas. Make a note of any questions you have. If these are not answered by the time you finish reading this module, ask your LTCO supervisor or the State LTCO for guidance.

Potential Action Steps to Determine Why Mrs. Bronner Says Her Purse is Missing

Potential Steps or Actions	**How Might This Step Help You?**

My Questions

After making a few notes, look at Tables 5, 6, 7 on the following pages. These tables list potential actions that you might take to determine what Mrs. Bronner really means when she says her purse is missing.

Table 5. Information that could help resolve complaint.

Talk with individuals	Seek Information Such as the Following:
Mrs. Bronner	1. A description of her purse 2. What she remembers about the purse, when she had it, where she keeps it, what she does with it when she uses it. 3. What actions Mrs. Bronner has taken to locate her purse. 4. Is Mrs. Bronner really wanting her purse or is she seeking something else, perhaps something that she associates with the purse? 5. Does Mrs. Bronner want your help? 6. Will she let you use her name if you talk with anyone else?
Mrs. Bronner's daughter, with Mrs. Bronner's permission.	1. What can she tell you about Mrs. Bronner's purse? 2. Has she taken any action regarding Mrs. Bronner's missing purse? 3. When did she last see Mrs. Bronner's purse? 4. If she thinks Mrs. Bronner is looking for something else, what might it be? 5. Has she had any experiences with other items missing in Peaceful Acres? If so, how has the facility responded?
Other residents with Mrs. Bronner's permission	1. Have they seen Mrs. Bronner with a purse? If so, when? What does she do with her purse? Does she take it whenever she leaves her room? Has she talked with them about the missing purse? 2. Have any of their possessions disappeared in the facility? Do they leave things out in their rooms? How do they keep things that are important secure? What is the experience of other residents related to retention and use of their own things? 3. What happens if something is missing?
With the Residents' Council or an officer	1. Has the Council dealt with issues of missing possessions? What actions did the Council take? 2. What happened when these issues were discussed? 3. Were these issues in the past or are they current issues?

Peaceful Acres staff, with Mrs. Bronner's permission	1. What do they know about Mrs. Bronner's purse? 2. What does the facility do with misplaced items—items that are found but staff cannot identify the owner? 3. What are the facility's policies for handling missing possessions?

After making a few notes, look at Tables 5, 6, 7 on the following pages. These tables list potential actions that you might take to determine what Mrs. Bronner really means when she says her purse is missing.

Table 6. Observations that could help resolve the complaint

Observe
1. Do you see a purse in Mrs. Bronner's room? 2. With Mrs. Bronner's permission and someone else present, assist her in looking in her closet, drawers and on the floor, for her purse. Follow the policies of your SLTCOP regarding looking for a resident's possessions. 3. Do you remember seeing Mrs. Bronner with a purse during any of your visits? 4. Do you see other residents with purses and using other personal items? 5. Is Mrs. Bronner's room located close to an outside entrance to the facility? 6. How are the entrances to the facility monitored?

After making a few notes, look at Tables 5, 6, 7 on the following pages. These tables list potential actions that you might take to determine what Mrs. Bronner really means when she says her purse is missing.

Table 7. Documents that could help resolve the complaint

Review Documents
1. What do federal and state laws and regulations say that might be relevant to this issue? 2. Do your notes or the LTCOP records on Peaceful Acres indicate similar problems? If so, when did they occur? What was the cause? What was the outcome? 3. If pertinent, review minutes from the Residents' Council's meetings, with their permission. 4. Look at licensing and certification reports from the facility to see if similar issues were cited. 5. Look at the facility's policies regarding missing belongings and security of possessions.

By engaging in the preceding activities, you are conducting an *investigation.* The steps you would ordinarily take to help you determine the reason Mrs. Bronner says, "My purse is missing," are the basics of a long-term care ombudsman's investigation.

The primary tools of investigation are: interviewing, observing reviewing documents.

STAGE 1: INTAKE, INVESTIGATION AND VERIFICATION

Intake and investigation is the initial stage in problem solving. It is fundamental to your ability to successfully resolve an issue. This stage includes three steps that are discussed in the following narrative: recognizing and receiving complaints; gathering information; and verifying and defining the problem.

Intake: Recognizing and Receiving Complaints

What is a complaint? This basic question is a confusing one for many ombudsmen. Are complaints only those problems you report to the State, only those you refer to a regulatory agency, or anything a resident voices as a concern?

In its simplest definition, *a complaint is any expression of dissatisfaction or concern*. However, this does not mean that you launch a full-scale investigation every time someone says today's lunch tasted bad. Many people express dissatisfaction just to let off steam or to have some way of expressing themselves about things over which they have little control. They may not expect or want you to intervene on their behalf. Some residents may be disoriented as to time and express concerns that relate to past events that are no longer relevant. Your task is to be skillful in listening, observing, and asking questions in order to determine when such expressions are actual requests for assistance or indicate a problem that you might need to pursue.

Identifying Unvoiced Complaints

Problems sometimes exist in a facility without anyone complaining about them. An absence of complaints may not mean that all the residents are receiving quality care or experiencing an acceptable quality of life. There are many reasons why residents are reluctant to voice complaints. Some of these were listed on the preceding pages; others are listed in the module, "Residents' Rights."

A lack of voiced complaints should be taken as an indication of the need to reach out to the residents. Regular visits in a facility will make you a familiar figure to the residents. Once you have established trust, residents and their families may begin to assert their rights and voice their concerns. Your ability to detect hints of residents' concerns that are not explicit and to observe situations that require action is as important as your ability to respond to a direct request for assistance.

Sources of Complaints

An ombudsman may receive problems or complaints from a variety of sources, including:

- Residents
- Relatives or friends of residents
- Local advocacy or friendly visitor groups
- Facility staff
- Social work and human service agencies
- Hospital personnel
- Legislators and political leaders

Most of your complaints will probably come from visits in the facility or from telephone calls to the LTCO office. If possible, cultivate relationships with staff members or residents who can contact you on behalf of residents with less ability to communicate.

There are three important factors to remember about sources of complaints:

a. Few residents will make a complaint unless they are visited regularly by an ombudsman. Most residents will not feel comfortable complaining to a stranger for fear of reprisal, and therefore need to know and trust a person before talking openly about their concerns. In addition, many residents do not know that they have the right to complain, or they feel that making a complaint will not do any good.

   In some facilities, a residents' council, grievance committee, or community council (composed of residents, relatives, and community people) may bring problems to you. Complaints made by such groups help to protect and support an individual resident. Sometimes these organizations become mere "rubber stamps" for the facility administration, so you will have to learn how much they really represent the interests of residents.

b. Relatives of residents are one of the most common sources of complaints. Family members may hesitate to complain for fear of retaliation to their loved ones. Families also fear that once the facility staff has labeled them as "complainers" or "guilty children," their credibility will decrease. Your visits in a facility will help families learn about the LTCOP.

   Keep in mind that needs and interests of families are not necessarily the same as the needs and interests of the residents. Residents face the stark reality of spending 24 hours a day in a facility and may feel a vulnerability that their relatives do not understand. Furthermore, residents' concerns may seem small to people living outside the facility but may have a major impact on residents' daily quality of life.

c. Long-term care staff members are a common, if not frequent, source of complaints. Staff complaints may be based on a variety of motives. On one hand, many staff are concerned about residents and want to provide the best care possible. When conditions in a facility are poor, staff may look for outside help in trying to correct the problems. On the other hand, some staff can become disgruntled with their employer because of low pay, poor working conditions, or other disputes with management. Since your role as a LTCO is to address concerns of residents, be careful to avoid becoming an ombudsman for facility staff. Offer to conduct in-service training programs or to share resource information with the facility to improve the environment for everyone who lives and works there.

Investigation: Gathering Information

Before you can resolve most complaints, you will need to gather additional information about the situation from a variety of sources. This process, which is the second step in Stage 1, is frequently referred to as investigation.

There are number of other officials whose responsibilities include investigating complaints or conditions in long-term care facilities. Some of these are: surveyors for the licensing and certification agency or the Fire Marshall's office, law enforcement officials, and adult protective services workers. Each of these has its own set of rules and standards of evidence that must be met in order to determine the validity of the complaint and any corrective actions or penalties that might be applied. Sometimes others expect a LTCO's investigation to adhere to the standards of investigation used in their job.

As a LTCO, your investigation and actions do not have to comply with the standards other use. Your primary role is to advocate, to act on behalf of residents. You can act on behalf of residents without gathering evidence that meets legal standards of proof. While you cannot be reckless, you have more freedom to think and act "out of the box" of regulations and objective procedures that others must use. Your actions must always be directed by residents, grounded in fairness, and in compliance with the law, regulations, and policies of your state's Long-Term Care Ombudsman Program.

The purpose of a LTCO's investigation is to determine whether the complaint is verified and to gather the information necessary to resolve it. Verified means that it is determined after work (interviews, record inspection, observation, etc.) that the circumstances described in the complaint are generally accurate.[6] An investigation is a search for information. You must seek information that will either prove or disprove the allegations made by the complainant. The successful resolution of a complaint often depends on the quality of the investigation. A poor investigation can lead to a valid complaint being dismissed.

It is important to be objective in gathering information. You must not make assumptions about the validity of a given complaint, even if you believe there are problems in a facility. Being an objective investigator does not mean that you lessen your efforts to improve the care and quality of life for long-term care residents. It means that you keep an open mind so as not be blind to evidence that does not fit a particular theory about the root cause. More explanation about this follows in a section, "When a Complaint Cannot be Verified."

The investigation involves preparation – deciding what information is relevant – and using various techniques to collect it. As stated earlier, the most common techniques ombudsmen use are interviewing, observation, and the use of documents. In order to use these techniques well, there are certain skills you need. These skills are discussed in relation to the relevant steps in the problem-solving process.

Preparation for an Investigation[7]

When you receive a complaint (intake), take time to adequately prepare before jumping into an investigation. How do you decide what information is relevant and how you might collect it? There are some basic steps to follow. Take a look at these steps and see how they apply to your work by reading about Mr. Michards' experience.

[6] Administration on Aging National Ombudsman Reporting System instructions recommended in 2006.
[7] Much of this section is adapted from the Oregon Long-Term Care Ombudsman Certification Manual, Section 7, Investigating Complaints. 2005.

STEPS TO PREPARE FOR AN INVESTIGATION

1. Separate the problems
2. Categorize the complaint and identify relevant laws or regulations.
3. Consider potential cause(s) or hypotheses.
4. Identify all participants.
5. Identify relevant agencies
6. Identify steps already taken.

Example:

Mr. Michards, a private pay resident, had been in the nursing home for several months when his wife started to notice a tremendous change in his behavior. Mrs. Michards says, "He became chronically sleepy at just about the time he began losing weight." She believes that her husband was placed on an improper diet. "How could he be given an appropriate diet when the doctor never sees him?" she exclaims to you, the ombudsman. "He loves milk, but it's always warm here. I bring him snacks and they're always gone. Just like his clothes. I am being overcharged terribly and they can't keep track of anything. I am still trying to get them to replace the hearing aid they lost two months ago! Can you help me?"

Step 1: Separate the Problems

Gather as much specific information as possible in your first contact with the complainant. Separate the problems in clear statements and rank the problems in order of importance to the resident or the complainant. This ranking will set the priority for which problems you address first. After you have a clear list of all the concern, go back and ask questions to fill in the details.

- Be sure to find out when the incident occurred. Is it a recent event or did it happen six months ago? The time frame might affect how much evidence you can find. It could also affect whom you interview and what kind of resolution will be sought.
- Find out where the incident occurred. If the situation occurred in the facility, it might be handled differently than if it occurred in the community while the resident was out for an appointment. The physical location within the facility might also affect the investigation and resolution.

Example:

a. Mr. Michards has experienced a sudden, unexplained change in behavior, becoming chronically sleepy. This began about a week ago.

b. Mr. Michards has experienced some weight loss, perhaps due to an inappropriate diet. He lost ten pounds in three weeks.

c. The doctor is not examining Mr. Michards often enough. He last saw the doctor two months ago.

d. Mr. Michards has lost his hearing aid. The complainant last saw it in its usual place on his bedside table a week ago when she left after dinner at about 6:00 PM.

e. Mr. Michards' milk is always warm. This is true at all meals. The milk is served in a plastic glass on the tray with a plastic wrap covering it. Mr. Michards cannot remove the cover without assistance.

f. Mr. Michards is losing his clothes. When Mr. Michards moved into the facility three months ago, the complainant brought in six pairs of socks, three pairs of pants, six shirts, six pairs of underwear and six T-shirts. The complainant does the laundry herself once a week. The complainant labeled the clothes as the facility instructed her to and added them to the inventory. Since admission, the complainant has had to replace three shirts, both pairs of pants, all of the socks and all of the underwear and T-shirts.

g. Mrs. Michards feels she is being overcharged by the facility. She pays a base fee of $3500 per month and then for some extra items that she can't specifically recall that vary each month.

Your problem statements should be detailed and concrete. They should be clearly agreed upon by both you and the complainant.

Step 2: Categorize the Complaint and Identify Relevant Laws or Regulations

Categorize the complaint, or in the case of a complex complaint, each of the individual elements. Know what kind of complaint you are dealing with.

Example: The warm milk complaint is a dietary problem.

Once you have categorized the complaint, research relevant law or regulations.

Example: The warm milk complaint is addressed in the federal "Requirements for Nursing Facilities"8, §483.35 Dietary Services (d) Food, "Each resident receives and the facility provides: (1) Food prepared by methods that conserve nutritive value, flavor, and appearance; (2) Food that is palatable, attractive, and at the proper temperature."

In other words, the law says milk should be cold!

Step 3: Consider Potential Cause(s) or Hypotheses

A hypothesis is nothing more than a beginning assumption about the nature of the problem. It is made in order to draw out and test its logical consequences. It is more than a guess. It is a set of propositions, assumptions and generalizations that possibly explain something. You might think of the hypotheses as a speculative theory. To put it another way, in developing a hypothesis you are considering possible causes.

Think of it this way. There are usually many reasons problems occur. Developing a theory, or hypothesis, allows you to list a possible cause or causes of the problem. Developing a hypothesis is what you were doing in working on Mrs. Bronner's missing purse complaint.

Example: What are the possible causes of the simple complaint about warm milk? In other words, what are your possible hypotheses?

a. The aides may be too slow in serving dinner.

b. The milk sits too long in the kitchen even before being placed on the tray.

c. The milk sits on the delivery tray too long in the hall prior to being serviced.

d. If Mr. Michards doesn't feed himself, perhaps he has to wait too long for assistance.

e. Mr. Michards can't feed himself and the staff aren't aware of it.

f. Mr. Michards might leave the milk on his tray as the last thing to be consumed.

g. There are not enough aides to serve the meals properly.

h. Mr. Michards is served last because his room is at the far end of a hall.

You might think of each of the above as a supposition to help inform your investigation. The list can help you select evidence for study and provide a sense of direction for the remainder of the investigatory process. What each of these hypotheses allows you to do is examine the issue of cause and effect in a careful, systematic and consistent way.

Step 4: Identify All Participants

Who is responsible and who has the power to do something about it? It may be important to gather names, telephone numbers, and addresses of all people who have some role in the situation. A complaint about resident care could include: the complainant, the resident, the facility nursing staff, the facility administrator, and the resident's physician. Another health care facility (hospital, nursing home) where the resident was recently treated may be an important contact in determining the cause of the resident's condition. In short, identify anyone who knows anything about the complaint or related circumstances and identify anyone who has the power to do something about the problem.

Example: Mr. and Mrs. Michards
Aides who assist with dietary services
Dietary supervisor
Mr. Michards' roommate or dining table companions

Step 5: Identify Relevant Agencies

Is there someone else involved? Is there another agency that needs to be involved? A case manager, protective services, a legal aid attorney, a representative of the Medicare fiscal intermediary, police, or another LTCO? If there is, they may have information or insights that you want.

Example: Licensing and Certification Agency (surveyors)
Local Health Department

Step 6: Identify Steps Already Taken

What work has already been done? Has the complainant taken some action? If the complainant has taken some action, you need to know this to avoid duplicating unproductive actions or retracing steps. You also need to know the results of the actions already taken. This can help you anticipate obstacles to resolving the problem. For example, has the complainant talked with the administrator, director of nursing, charge nurse, or supervisor? Has the complainant contacted the physician? Have there been any meetings with the staff? Have any other agencies been contacted?

If the complainant has not taken any action, you can suggest possible steps he/she might take. Advice of this nature helps the complainant learn self-advocacy and may also save you time to work on other problems. Remember, you should encourage and support self-advocacy whenever possible.

Example: Who has Mrs. Michards talked with about her complaints?
When did she talk with them?
What response did she receive?
Has she filed a complaint with anyone else?

Step 7: Clarify the result the complainant is seeking.

What outcome does the complainant want? Is it the same outcome the resident wants if the resident is not the complainant? By determining the answer to this question, you might save yourself some time and prevent your solving the problem the "wrong" way.

You may see a need to effect policy changes or systemic solutions, but the complainant only wants his/her immediate situation improved. You might have the opportunity to work on the more long-range solutions, but your primary focus should be on the complainant's immediate concern.

Example: Mr. Michards will have cold milk to drink.

Mr. Michards will be able to eat the snacks that Mrs. Michards brings whenever he wants them. Staff will offer the snacks to Mr. Michards and will keep them in a labeled container for his exclusive use.

Interviewing

Interviewing is possibly the most frequently used method of gathering information. In order to discover the facts of a case (the who, what, when, where, why, and how), you might interview a resident, administrator or operator, or an employee of another agency or institution. Regardless of the position of the person being interviewed and the personal style of the interviewer, there are several factors to consider when preparing for an interview. Following a few guidelines will increase your likelihood of success. You need to be skillful in listening, questioning and note taking.

FACTORS TO CONSIDER WHEN PREPARING FOR AN INTERVIEW	
Setting	Is it comfortable, quiet, and private?
Time Allotted	Will the interview be hurried?
Timing	Will there be interruptions?
Goals	What are the goals of the interview? List these.
Biases	What possible biases do you have? How will they affect the process and the outcome? What preconceived ideas might the interviewee have?

Many of the factors may be beyond your ability to control. For example, you may not be able to see an administrator at a time and place of *your* choosing. The most important item, however, is one you *can* control: Set your goals beforehand. Know what questions you need answered and what specific information you need. What gaps in your knowledge about a complaint are you seeking to fill?

As a general rule, ***it is best to speak to the complainant first*** before securing additional information from other residents, facility personnel, family, or other people. If the complainant is someone other than a resident, talking with the resident next is your second interview. As a LTCO you work on behalf of the resident.

Remember that an interview is a social situation, and that the *relationship* between you and the interviewee will affect what is said. Although you will want to direct the interview in order to achieve its goals, most of your time will be spent *listening*.

It is extremely important to avoid making promises to the complainant regarding the resolution of the problem. It can be tempting, in a sincere effort to comfort a resident, to

assure him/her that the problem will be solved. This can lead to false expectations which may eventually be turned against you.

GUIDELINES TO FOLLOW DURING INTERVIEWS

Maintain objectivity. Do not make assumptions about the validity of the information.

Try to establish rapport before addressing the problem.

Explain the purpose of the interview and the function of the ombudsman.

Use open-ended questions to encourage responses about the problem area such as "What is it like to participate in your care planning meeting?" or "What happens when you ask for a different meal than the one on the menu?"

Use close-ended questions to obtain specific details and facts such as, "Who responded to your request for assistance?" or "Do you get outside the facility for fresh air?"

Use language that is easy to understand; explain any technical terms.

Guide the interview toward the desired goals, yet be flexible enough to follow-up on any new, relevant information received.

Let the interviewee know when the interview is about to end; summarize what has been accomplished.

Explain how the information will be used and other steps anticipated in conducting the investigation and resolving the complaint.

Skills Involved in Interviewing

The charts on the following pages define and explain the skills involved in each activity.

They are:

- Listening
- Questioning
- Note taking

Interview Skill #1: Listening[9]

GUIDELINES FOR LISTENING DURING INTERVIEWS

Be yourself. Use words, skills and body language appropriate to the situation in a way that fits your personality.

Be an active listener. Listen appreciatively and with understanding. Reduce defensive communication by reflectively listening. Try to be empathetic but get the interview back on track. Treat the interviewee with respect. Try to understand their point of view. Let them explain their perspective.

Be alert to more than spoken words when you listen. Notice inflection of speech, qualities and tone of voice, facial expressions, a glint in the eye, body language, gestures, and general behavior. See if you can detect gaps or omissions in what the person is saying. Sometimes more can be learned from what is not said than from what is said.

Determine whether the complainant is glossing over some fact because he/she thinks it "detracts from his/her position." Explain that you are interested in the "bad" facts as well as the "good," and that you can only be of help if you know the whole situation.

Be comfortable with silence. Don't rush to fill the gap. Use silence to organize what you've heard. Be patient.

Never completely believe or disbelieve everything a person says. Distinguish facts from someone's opinion, hearsay, characterization, or evaluation. You will have to sort out the difference between the "truth" and fiction. If someone labels a resident as "hostile," for example, find out why (e.g., specific behaviors the resident exhibits, how often, with what people).

Remember that you are the interviewer. Don't let yourself be interviewed or drawn in personally. Turn questions into statements and reflect them back. A complainant may ask, "Don't you think they are short staffed here?" Your reply could elicit more information, "It sounds like you think there is not enough staff. I'd like to know what leads you to that conclusion."

Be alert to problems that may be unintentionally revealed. The resident may have a very

limited notion of what help is available to him/her or may not want to "burden" you with too many problems. Listen for "the problem behind the problem." There is always the possibility that what the complainant is saying is not what is bothering him/her, but is instead voicing feelings that reflect a general feeling of hopelessness.

Stick to your interview agenda. Don't be deflected or distracted by collateral issues. Avoid debates—they are win/lose affairs. Don't offer any information.

Stay focused on the current issue. Don't talk about prior grievances.

Know and be prepared to cite your investigative authority as a LTCO (State and Federal law).

[9] Adapted from the Oregon Long-Term Care Ombudsman Certification Manual, 2005, and the Louisiana Long-Term Care Ombudsman Resource Manual, 1999.

Interview Skill #2: Questioning

As mentioned under “Guidelines to Follow During Interviews,” in this module, different types of questions may be used to gather information. Think through what you want from the interview and then develop questions to help you obtain the information. Table 8, The Questioning Technique, prepared by Robert K. Burns of the University of Chicago, lists various types of questions, the purpose of each, and examples. Refer to it for suggestions as you design interview questions. This table will also be helpful when you are preparing for a meeting to resolve the complaint.

Table 8. The questioning technique.

Type	Examples	Purpose
Factual or "W" Questions	1. All the "W" questions: What, Why, When, Who, Which, How?	1. To get information
Explanatory or "Dig Deeper" Questions	1. In what way would this help solve the problem? 2. Just how would this be done? 3. What other aspects of this should be considered?	1. To broaden discussion 2. To get deeper thinking and analysis 3. Get at additional facts, reasons, and explanations
Leading or "New Idea" Questions	1. Should we consider this as a possible solution? 2. Would this be a feasible approach?	1. To introduce a new idea 2. To advance a suggestion of your own or others
Hypothetical or "Suppose" Questions	1. Suppose we did it this way...what would happen? 2. Another company does...is this feasible?	1. To change the course of the discussion 2. To suggest other, or even unpopular opinions and points of view
Justifying or "Show Proof" Questions	1. Why do you think so? 2. How do you know? 3. What evidence do you have?	1. To challenge old ideas 2. To get reasoning and proof 3. To develop new ideas
Alternative or "Make a Choice" Questions	1. Which of these solutions is best, A or B? 2. Does this represent our choice in preference to...?	1. To make a decision between alternatives 2. To get agreement
Coordinating or "Get Agreement" Questions	1. Can we conclude that this is the next step? 2. Is there general agreement on this plan?	1. To develop consensus 2. To get agreement 3. To take action

Interview Skill #3: Note taking

Your notes will be part of the file, which is the central reference point not, only for you and the complainant, but also for agencies to whom the complaint may be referred.

TIPS FOR EFFECTIVE NOTE TAKING

Maintain rapport and a good conversational flow during an interview even if it is necessary for you to take notes.

If you will be taking notes, explain the reasons why in order to relieve any anxiety or fear on the part of the person being interviewed.

Take notes of responses that are especially significant and/or that you feel are important to remember accurately.

Write only information that you are prepared for the interviewee or someone else to see.

Keep your notes short, factual, and to the point. It is acceptable to include your personal observations and judgments; however, substantiate these with facts. For example, if you indicate that the floor was dirty, state that you noticed coffee and juice stains in the day room on Wing C, and that it felt sticky to the touch.

Avoid judgmental statements such as “Resident is obviously a chronic complainer,” or “Administrator can’t be trusted.”

Describe behaviors, do not attempt to label them. For example, if an administrator is unresponsive to your questions say, “Administrator said he had no comment when I asked about the training and supervision that certified nurse assistants receive. After I asked other questions related to the complaint, the administrator said the interview was over and escorted me to the door.”

In other words, substantiate and document your opinions and observations with as much information as possible.

Interview Record Checklist

Include the following information in your record of an interview:

- Names and positions (job title) of everyone present, whether or not they spoke
- Narrative account of the content of the interview
- Date and time of interview
- Location of interview
- Goals that were accomplished and those that were not achieved
- Any new avenues to explore

Observation

Observation is the second most common method of gathering information. Many complaints can be understood and verified only by sharing in the experience of the complainant. Complaints that have to do with items such as staffing, sanitary conditions, and food often can be fully checked only through observation. This section includes tips for observation and a list of questions intended to help you focus on the information that is presented to each of your senses.

TIPS FOR OBSERVATION

When observing conditions in a facility, it is important to use all the senses. Refer to Table 9 on the following page for factors to consider.

Approach a situation requiring investigative observation with an open mind and an understanding of what is observed.

Be as impartial as possible. If you look only for evidence that fits a preconceived notion or theory, other evidence may be missed or much of the evidence may be misinterpreted.

Prepare for observing by deciding what type of observations will help you investigate a particular case.

For example, in a complaint about a resident being given a regular meal instead of a salt-free dinner, you would be able to investigate by seeing and possibly tasting the food served. By making an unannounced visit to the facility, you could observe a routine mealtime procedure. Familiarity with applicable rules and regulations will allow you to better judge which observations are relevant to the individual case and which are extraneous.

Record your observations as soon as possible after they are made to help eliminate errors due to a memory bias, (for example, recording what you expected to find instead of the actual facts of your observation).

Table 9. Guide to sensory observations in a long-term care facility.

Sight	Sound	Smell	Taste	Feel
Do furnishings appear cold, institutional, hard? Are they homelike? Does each resident have a locker or dresser? Are there enough chairs for visitors? Are there pictures calendars, photos, or art work? What colors are the walls? Bright? Cheery? Dull or drab? Is the paint peeling? Are the plants real? Does the facility make maximum use of natural light? Are residents clean, shaved, hair combed? Are clothes wrinkled? Dirty? Are call lights left unanswered? Is the staff neat? Do they smile at residents? Do they wear name tags or have an identifying uniform? Are there several blocks of idle time each day without activities? Are food trays left out with uneaten or spoiled products?	Is music piped through corridors too loud or too soft? Is it appropriate for residents? Are calls bells ringing often and long? Are there residents with noticeably labored breathing? Are all "noisy residents" in one area? Do staff talk pleasantly with residents? With one another? Do they call each other by name? What statements are made that affect residents' dignity? Is an intercom overused and annoying? Are residents involved in activities that promote conversation? Are visitors loud and disruptive because they don't have a private place for group gatherings?	Is there a strong urine odor? A strong disinfectant order? Do residents smell of urine or feces? Does the food smell inviting? Do residents smell of colognes, after shave, or perfume? Are air fresheners or other scents used to mask unpleasant odors? Is there an odor from dead flowers, medicine, or alcohol? Is there rotting or spoiled food aroma? Are the chemicals from the beauty shop overwhelming?	Are smells so strong they can be tasted? Is the food cooked completely? Is the coffee cold? Is the water fresh? Are the "chilled items" served at room temperature? Is the fruit fresh? Is the milk sour?	Are sheets soft or stiff? Are blankets scratchy or smooth? Is the building too hot or too cold or residents? Are the floors slippery or gritty? Are the resident's hands cold, skin stiff? Do the wheelchairs fit the size of the resident? Are the stationary chairs upholstered for comfort? Are the safety grab bars secured in the bathrooms and shower areas?

Using Official Documents[10]

Using official documents is the third most common method of gathering information. Documents such as laws and regulations tell you the legal requirements that apply to facilities and the legal protections those residents (consumers) have. Other documents such as survey records or resident records provide information about a facility's actions.

There are many types of documents you might review during an investigation. Focus on the ones that are likely to give you the additional information that you need to verify and resolve a complaint.

In the early stage of an investigation, it is helpful to read the sections of the laws and requirements or regulations that apply to the complaint. Knowing the applicable provisions helps you decide what to cover in an interview, who to interview, and what to observe.

Access to Resident Records

There are provisions in federal and state laws and regulations regarding the confidentiality of resident records and resident and ombudsman access to these records. The basic provisions are summarized in the table that follows. If you need to know the exact language of these provisions, look them up from the list of references at the end of the table. If issues arise regarding access to resident records, consult with your LTCO supervisor or with your SLTCO.

A resident's records are defined in the Medicare and Medicaid Requirements as all records pertaining to him or herself including clinical records.11 These records might include social, medical, financial, and contracts or statements or forms signed as part of the admission process. Typically, these records are located in different places in the facility - they are not all in one chart.

When to Access Records

Since your role as a LTCO is to *empower* residents and their families, whenever it seems appropriate to examine a record, always suggest that the resident ask to review her own record. If the resident wants assistance in understanding what the record contains, she can ask a trusted staff member to explain it or ask you to go through it with her. The resident has the right to have the record explained in everyday terms. There will be times when this action is not possible and you will need to review the record to glean the pertinent information.

[10] Much of this section is adapted from the *Access Module*, Illinois Long-Term Care Ombudsman Program. Sara S. Hunt. August 2001. Available on www.ltcombudsman.org

TIPS FOR WHEN LOOKING AT RESIDENT RECORDS MIGHT BE APPROPRIATE

A resident wants to know information that the records contain such as: what is written on her care plan, what the physician ordered, or what financial transactions have been made.

In investigating a resident's complaint, you receive conflicting or vague information from staff. Looking at the record will provide another data source that is necessary to understand the issue.

Consulting the record is essential to verifying the information you have received regarding the resident's complaint.

You need factual information from the record such as information about guardianship, durable power of attorney, contact information, the number of times physician visits or contacts were documented.

In most problem-solving situations, you *will not* need to look at the resident's record. You will be focusing on what is or is not being done—the *results* and the *impact* on the resident—not on what is documented in the record. The staff might consult the record to assist them in talking with you and the resident about how to get the results the resident is seeking. When staff look at the record, they might spot problems or gaps in care and identify solutions themselves.

Further considerations when deciding whether to look at a resident's record is that records are sometimes not complete or totally accurate and that they may be difficult to understand. Records are sometimes filled out hurriedly or by staff who do not understand the significance of careful record-keeping. In cases where you do not understand the record, you should consult a specialist to help you.

Because of the confidentiality provisions regarding resident records, facilities usually are appropriately very protective of these documents. When you ask to see someone's records, the facility might be wary, wondering what complaint you are investigating and what you are trying to determine. You might encounter some resistance or a lot of questions. Staff might be defensive and feel you are "checking up" on them. Therefore, you need to follow the preparation tips below.

TIPS FOR PREPARATION TO ACCESS RECORDS

Equip yourself by having the following before you ask for a resident's record.

A firm knowledge of the legal basis for your request,

The appropriate consent to release records form completed, and

Ideas about what to say if you encounter resistance or questions about your case.

Depending upon the circumstances you might give a response similar to the ones below.

- Mrs. Fisher has the legal right to authorize me to look at her medical record. I've given you her consent form. Please give me her record now.

- If I need help understanding the record, I'll let you know. I just need to review the record by myself right now.

- At this point, I'm looking for information. I haven't determined if there is a problem.

- Due to ombudsman confidentiality policies, I cannot discuss specific details with you. If there is an issue that needs your attention, I'll let you know.

Determining a Resident's Ability to Make Decisions [12]

There are three primary principles that guide decision-making:

1. Informed consent
2. Best interest
3. Substituted judgment

If a person has decision-making capacity, the doctrine of informed consent applies.

1. Informed consent: An individual can exercise autonomy in making a decision. The individual has:

- Relevant information about the proposed treatment or research,
- Freedom of choice in a non-coercive environment,
- Competency to make and communicate a decision.

2. Best interest: This principle is acting in the interests of someone's well-being, health, and welfare.

- It implies that the benefits of treatment are weighed with the burden of treatment.
- Patient health and welfare are the controlling values.

3. Substituted judgment: A decision-maker, other than the individual, attempts to decide about the acceptability of interventions as the person would have decided had he or she been competent.

- Individual autonomy, following what the individual wants or would choose, is a priority value.
- This decision-making process uses, as a primary consideration, what is known about the person's values and preferences.

[12] Adapted from Working Through Ethical Dilemmas in Ombudsman Practice. Sara S. Hunt. National Long-Term Care Ombudsman Resource Center, 1989.

In working with residents, LTCO use decision-making principles in the following order.

1. **Informed consent:** Seeking to be sure the resident has information about options and consequences and is making a decision in a non-coercive setting.

2. **Substituted judgment:** Focusing on what the resident would want often means trying to get the relevant individuals talking with each other.

3. **Best interest:** Asking the relevant individuals to jointly discuss a range of options and residents' rights in making a decision.

There is a danger that best interest or substituted judgments may be used even when the resident has capacity. It is sometimes simply more convenient to rely on others—family members or medical professionals. The ombudsman may need to assist the resident in making her voice heard in these situations and by modeling reliance on the resident's decision-making capacity.

Residents with a Legal Representative

Residents who have a legal representative with decision-making power still retain some ability to participate in their care and exercising their rights. In some cases this is obvious by the type of decision-making mechanism. For example, power of attorney[13] is a shared decision-making tool with the resident retaining the ability to make her own decisions. A resident with a durable power of attorney for health care still has a voice in her care unless she is unable to make the decision. Residents with guardians still need to have their desires and preferences considered even if the guardian has the legal responsibility over that area of decision.[14] With a power of attorney or a guardian, LTCO need to determine what decision-making rights the resident has or can exercise. Sometimes family members with power of attorney usurp the resident's decision-making.

13 A power of attorney is an agent who does what the resident says to do and only for the time period specified by the resident in the power or attorney.

14 Centers for Medicare and Medicaid Services. The Interpretive Guidelines. State Operations Manual, Revision 5, 11-19-04, Appendix PP §483.10(a)(3)(4).

Table 10. Resident access to records in a nursing facility.

Situation	Procedures for Access
Resident or the resident's legal representative wants to see resident's records	Inform the resident or legal representative that they have the right to see the resident's records: 1. with written or oral request; 2. within 24 hours excluding weekends or holidays; 3. copies may be purchased at a cost not exceeding the community standard charge for photocopies and with two working days advance notice

Legal References

Nursing Home Reform Law. United States Code, Vol. 42, §1396r(c)(1)(A)(iv) and §1395i-3(c)(A)(iv). Medicare & Medicaid Requirements for Long-Term Care Facilities. Vol. 42, *Code of Federal Regulations*, §483.10 (b)(2)(i)(ii), §483.75(l)(4)(iv).

Table 11. Long-term care ombudsman access to resident records in a nursing facility.

Situation	Procedures for Access
Resident *is capable* of giving consent	Permission of the resident: 1. use *written* consent form. 2. verbal consent when resident is physically unable to sign document. Staff probably will want to verify consent with the resident. Document consent in LTCO case record. 3. LTCO exercises judgment regarding resident's ability to give informed consent.
Resident *is not capable* of giving consent	1. Permission of the resident's legal representative. Be sure this person has the *legal authority* to grant access to the resident's records a. Under a durable power of attorney: the agent or attorney-in-fact (power of attorney) b. The surrogate decision-maker may be the individual making the health care decision. c. A guardian, appointed by a court whose authority includes the pertinent records 2. Obtain *written* consent.
Resident *is not capable* of giving consent *and* has a legal representative and the issue is regarding the legal representative *or* the legal representative cannot be located within 24 hours despite a reasonable effort.	1. Get the approval of your SLTCO to access resident records without consent. 2. Use any relevant forms from your SLTCOP. 3. Document your assessment of the resident's inability to give consent, the use of a form, and your consultation with the SLTCO in the LTCO case record.
Resident *is not capable* of giving consent, the *legal representative is unknown***,** and you believe that the *records will be immediately altered* by staff pursuant to your record review.	1. Get approval to access records without consent from the SLTCO. 2. Use any relevant forms from your SLTCOP. 3. Document your assessment of the resident's inability to give consent, the use of a form, and your consultation with the SLTCO in the LTCO case record. 4. Request a copy of the record. 5. Obtain the name of the legal representative. 6. Within 24 hours you must seek immediate contact with the legal representative, updating him on: the

	complaint, current investigation, and any findings.
Resident *is not capable* of giving consent and *does not have* a legal representative.	1. Be sure a review of the records is necessary to investigate or resolve a complaint or to protect the rights of the resident 2. Get approval from the SLTCO to access resident records without consent 3. Keep a copy of any relevant, completed forms from the SLTCOP with your case records. 4. Document your assessment of the resident's inability to give consent and the use of this form in the LTCO case record. Use any relevant forms from your SLTCOP. 5. Document your assessment of the resident's inability to give consent, the use of a form, and your consultation with the SLTCO in the LTCO case record.

Legal References

Older Americans Act of 1965, §712(b); Nursing Home Reform Law. United States Code, Vol. 42, §1396r(c)(1)(A)(iv) and §1395i-3(c)(A)(iv); Medicare & Medicaid Requirements for Long-Term Care Facilities. Vol. 42, *Code of Federal Regulations*, §483.10 (b)(2)(i)(ii), §483.75(l)(4)(iv)

TIP FOR OMBUDSMAN PRACTICE
AVOID SHORTCUTS TO ACCESS

Your access to resident records is based on your following the procedures in the preceding tables in accordance with state and federal laws. You may encounter a situation where someone other than the resident or complainant offers to show you the resident's record. Unless you have access to the record according to the LTCOP procedures, do not look at the record.

Example:

Mr. Farley, a resident, shares a concern and asks you to intervene with the facility on his behalf. He gives you permission to use his name. Access to his records is not discussed since you do not anticipate needing to examine his records to deal with the issue. As you are gathering information pertinent to Mr. Farley's concern, the charge nurse talking with you tries to show you his record to prove the truthfulness of her response.

• Simply state, "I have not discussed reviewing medical records with Mr. Farley. I only want to know how often he has physical therapy and when his next appointment is."

Rationale for this type of response:

• You do have permission to reveal Mr. Farley's identity to work on resolving his issue.

• You do not have his permission to look at his entire medical record.

• You are seeking only the necessary information to understand and resolve the issue. If you determine you need to review his record, you will obtain his consent to access his record.

The difference in your asking for information when you are investigating a problem and in looking at that information in a resident's record that a staff person wants to show you is subtle but important. Ombudsmen work to support and encourage residents in exercising their rights; thus, LTCO are responsible for modeling respect for residents' rights.

• If you take a tempting shortcut and look at a record without permission, it will be difficult for you to hold staff to strict standards of confidentiality of resident information.

• If this staff person later realizes she showed you a chart without seeing a release form, she may feel you used her or took advantage of the situation.

• Staff may view you as someone who upholds residents' rights only when it is convenient.

LTCO model respect for residents' rights.

Other Documents

In addition to resident records, there are many other sources of information about facilities that you might want to exam. Some documents are available in facilities such as menus, staffing ratios, activity calendars, and facility policies. The most common documents from other sources are listed and briefly discussed.

Information Available from the Federal Centers for Medicare & Medicaid Services or the State Licensing and Certification Agency

1. Ownership: Facilities receiving federal money must declare ownership information. This information is disclosed on the facility's cost report and on the facility's licensure record which can be obtained from the state Medicaid agency or the licensing and certification agency. General information about facility ownership is posted on the Center for Medicare & Medicaid Services (CMS) website under Nursing Home Compare, http://www.medicare.gov/NHcompare.

2. **Cost Reports:** Facilities report financial operating information to the government on this document.

3. Survey Results: The Statement of Deficiencies (CMS-2567) and the Statement of Isolated Deficiencies must be available in the facility. The CMS-2567 is generated by the most recent standard survey, any subsequent extended surveys, and any deficiencies resulting from any subsequent complaint investigations. The CMS-2567 becomes public information 14 days after it is received by the facility.15 assessment The facility must submit its plan of correction for each deficiency to the licensing and certification agency for acceptance. Selected information from the survey report is available by facility and by state on the CMS website under Nursing Home Compare, http://www.medicare.gov/NHcompare.

4. Quality Measures: Quality measures information comes from resident data that nursing homes routinely collect on all residents at specific intervals during their stay. The information collected pertains to residents' physical, clinical conditions and abilities. This information is available by facility on the CMS website under Nursing Home Compare, http://www.medicare.gov/NHcompare.

5. Nursing Home Staffing: Nursing staffing information comes from reports that the facility reports to its state licensing and certification agency. It contains the nursing staff hours for a two-week period prior to the time of the state inspection. CMS receives this data and converts the reported information into the number of staff hours per resident per day. This information is available by facility on the CMS's website under Nursing Home Compare, http://www.medicare.gov/NHcompare.

6. Waiver of Nursing Services: Waivers can be granted by the State Licensing and Certification Agency to a facility from the requirement to provide licensed nurses on a 24-hour basis and/or the requirement to provide services of a registered nurse for more than 40 hours a week.

7. Nurse Aide Registry: The State maintains a registry of certified nurse assistants who have been convicted of abuse, neglect, and/or misappropriation of resident property (theft). You can search the registry by the individual's first and last name or by Social Security number.

Information Available Through Public Records

1. **Guardianship:** A record of a guardianship is available in the legal records of the local court of jurisdiction in which the guardianship was executed.

2. **Ownership and financial information for facilities that are publicly traded:** Corporations file a number of reports such as: a 10-K or Annual Report and a DEF 14-A or Proxy Statement. Both of these reports contain useful information about the management, budget, number and locations of facilities, and stock ownership.

3. **Information about individuals who are licensed professionals,** such as doctors, nurses, therapists is available from the state board(s) that regulates professionals: You need to know the correct spelling of the registered name of the individual.

Information Which is Not Required by Federal Law to be Available to LTCO[16]

1. **Incident report:** This is a report of incidents or accidents that occur within a facility.

2. **Quality Indicators Report:** This report contains information about resident functioning based on the resident assessment and can be used as a quality improvement tool. This is generated for each individual resident and for each facility. The State Licensing and Certification Agency generates and maintains this information. At this time, these reports are not required to be available to LTCO and the public. In some states, the Quality Indicators reports by facility are shared with LTCO. The Quality Measures listed in a previous section are based on the Quality Indicators and are posted on the CMS website.

3. **Notice of involuntary transfer and discharge:** Although a copy of this notice is not required to be sent to LTCO, the notice *must* contain information regarding how to contact the ombudsman.

4. **Reports of complaint investigations by the State Licensing and Certification Agency:** As stated above, any deficiencies resulting from a complaint investigation are public information; the report of the investigation is not.

Verifying and Defining the Problem

Verifying and defining the problem is the third and last step in Stage 1 of the problem-solving process. It involves verifying that the complaint is valid and then defining the underlying problem.

When a Complaint Is Verified

A complaint is *verified* if it is determined after work (interviews, record inspection, observation, etc.) that the circumstances described in the complaint are generally accurate. You have been gathering information in order to determine the facts of the case. Formal verification is simply a matter of

- reviewing those facts,
- ensuring that you have proper *documentation*, and
- deciding if the information supports the allegations in the complaint.

The amount of documentation and formal verification you need will be determined by the complexity of the issue, the willingness of the facility to accommodate the resident, and in some cases, the resident's cognitive and communication abilities.

When a Complaint Cannot Be Verified

There will be times when a complaint *cannot* be verified. There may be no corroborating statements, or the facts may even contradict the complaint.

Example:

> Mr. Johnson tells you that the Pleasant Manor assisted living facility didn't have enough staff to bathe and dress his mother on Tuesday two weeks ago. His mother has Alzheimer's. When you visit the facility, the residents all appear clean and appropriately dressed. Mrs. Johnson, the complainant's mother, does not recall any problems with dressing and bathing. Your casual conversations with other residents reveal nothing pertinent to this issue: there are no issues with insufficient staff or with residents not receiving assistance with bathing and dressing. Survey reports from this facility as well as your complaint documentation do not mention anything relevant to this issue. The residents' council and family council meetings have not expressed complaints that are similar. You have nothing to proceed on except Mr. Johnson's statement.

Handling these situations will require tact, as the resident/complainant may still be convinced that the problem is valid. Here are some tips:

- Be careful that you do not make the complainant believe you think he/she is foolish.
- A factual, detailed presentation is especially important when telling the complainant that nothing else can be done.
- Explain that not being able to verify the complaint does not mean that you question the honesty or sincerity of the complainant.
- Discuss any alternative steps that might be available. For example, there may be another agency better suited to deal with the complainant's concern.
- Suggest that the complainant begin to document his or her observations and other information relevant to the problem.

In some cases, *you can still pursue resolution without objective verification.* You may believe that a case has merit although you have been unable to verify it. It is also possible that you have been unable to get access to records or materials that might verify the complaint. In such cases, consider the following actions.

• **Help the resident or complainant represent him/herself.** Explain that there is little you can do at this time without further proof. Show the person how to document problems as they occur. If needed, explain the "chain of command" in the facility so the individual will know who to talk with if the problem comes up again. Leave telephone numbers and addresses of the LTCOP and other appropriate agencies for future contact.

• **Do whatever you can to resolve the complaint.** Complaints can be resolved without verification in many cases. If the resident complains that the staff is slow to answer his/her call light, you can always discuss the problem with the Director of Nursing (DON), **if** the resident approves. This may cause the DON to initiate her own investigation or quietly resolve the problem.

Defining the Problem

What is the problem? Your investigation may reveal that the root problem is not the one that was reported to you. For example, you may have been told that articles of clothing are being stolen. During your investigation you may learn that clothing is simply not being returned from the laundry room.

Accurately determining the root problem is essential to finding a lasting solution. Examine the information you gained by interviewing, observing, and reviewing documents. Ask yourself, "What is the problem?" Be clear about the root, or the underlying, problem before you try to resolve the issue.

SUMMARY

The purpose of a LTCO's investigation is to determine whether the complaint is verified and to gather the information necessary to resolve it. Ombudsmen use interviews, observations, and documents to gather factual, objective information about a problem.

Core Principles of the Long-Term Care Ombudsman Program [17]
Complaint Handling

• Complaints are resident driven. They begin with the resident, focus on the resident, and end with the resident. When someone else refers a complaint, the ombudsman determines, to the extent possible, what the resident wants before intervening.
• Complaints are confidential. Ombudsmen do not reveal the identity of a resident without permission.
• Complaints call for empowerment. Ombudsmen provide information and encouragement to residents or complainants to act on their own behalf with minimal involvement from the ombudsman.
• Though there are many persons involved in a resident's care, the primary focus of the ombudsman is the resident her/himself.

[17] http://www.nursinghomeconcerns.com The KIPDA Long-Term Care Ombudsman Program website. Louisville, KY. 2005.

APPENDIX D: THE PROBLEM-SOLVING PROCESS: GUIDELINES FOR PRACTICE

The Problem-Solving Process: Investigation Guidelines for Practice

Developed by Sara S. Hunt, Consultant

As an ombudsman you are responsible for resolving problems on behalf of residents. Regardless of the complexity or simplicity of the issues, there is a standard process you will follow in problem-solving. *This process is dynamic, not rigid.* The amount of time you spend in each step of this process will vary depending upon numerous factors such as:

- the type of facility: one with large numbers of staff and residents or one with a few caregivers and a few residents;
- the complexity of the issue;
- the amount of additional information you will need to be able to understand the issue;
- the number of individuals involved;
- the time factor if meetings need to be attended or appointments made; and
- the responsiveness of the facility to addressing residents' issues.

In an assisted living facility with a few residents, your approach to resolving problems might be much more informal than in a facility that is larger.

One of your primary missions is to *empower* residents and their family members to resolve problems by themselves. You want to help them have a sense of confidence that they can successfully address issues. You do this by providing information, guidance, and support. If necessary, you go with them to discuss issues with facility personnel or others. The information in these guidelines will also be helpful in your coaching a resident or family member in working through a problem. The process you use as an ombudsman is the same one you'll be advising residents or their family members to use.

The Problem-Solving Process

STAGE I INTAKE AND INFORMATION GATHERING
Receive the Problem Receive problems, complaints, concerns **Gather Information** Collect information from interviews, records, observation **Define the Problem to be Addressed** Review information gathered. Analyze to determine what seems to be the problem. The initial problem or complaint may be only a symptom of an underlying issue.
STAGE II **ANALYSIS AND PLANNING**
Analyze the Situation Once you identify the problem, consider the causes. **Consider Solutions** Generate alternative solutions or approaches. Who should be involved? When? How? Why? **Identify Obstacles** Anticipate obstacles to help select an appropriate approach.
STAGE III **RESOLUTION AND FOLLOW-UP**
Choose an Approach From your list of alternative solutions, choose the most effective way to proceed, keeping any obstacles in mind. Identify alternative strategies in case you need them. **Pursue Resolution** Proceed with the selected plan, but be flexible with alternatives. **Evaluate the Outcome** Check back with the persons involved to evaluate the outcome. Is the problem solved? Is it partially solved? If not, look for new approaches, information, etc., and start again.

A Quick Reference for Problem Solving

The following list of questions is a “ready-reference” to use in thinking through issues and how to proceed. It is not a comprehensive list nor is it rigid in its order of steps. It’s a guide to help clarify thinking and to ensure that you haven’t overlooked a key part of the problem-solving process. As previously mentioned, there will be times when problems can be quickly addressed. Resolving problems will not always require such a detailed analysis and resolution process as the following includes.

You can also use this reference to guide your conversations with residents and family members who turn to you for advice regarding working through issues on their own.

Stage 1: Intake and Information Gathering

Receive the Problem: Intake

A. Listening

What is the resident* telling you?

Are any problems or concerns being expressed?

What is being omitted, or glossed over, in the conversation? Is there a problem or concern that isn't being stated directly?

Is this an issue that ombudsmen address? (Refer to your SLTCOP for further guidance.)

B. Checking with the Resident

What actions has the resident taken regarding the problem?

What response did the resident receive?

What does the resident want?

Does the resident want any assistance from you such as information, suggestions about additional steps to take?

Is the resident willing to act on her own behalf in pursuing further action? Does she/he want encouragement, guidance, or support from you?

If the resident wants you to be directly involved, will she work with you and be present with you in meetings with other individuals?

Will the resident allow you to identify her while you are gathering more information about the situation and trying to resolve it?

* Resident will be used throughout this section with the understanding that you will hear problems from many sources such as family members or staff.

Receive the Problem: Information Gathering

Information gathering primarily occurs in three ways: interviews, observations, and review of documents.

A. Interviews

Are there individuals, other than the resident, you need to talk with to help you better understand the problem? In deciding who to talk with consider the following.

Who has the resident talked with about the problem?

Is the problem is widespread, affecting several residents, or affecting only one resident? You might need to determine the prevalence of the problem via interviews.

Has the resident council discussed or addressed this issue?

Who has the authority to change the situation, to resolve the problem?

Other than the resident, who might be most knowledgeable about the problem or about contributing factors such as facility policies and practices?

Who do you want to interview?

Why do you want to talk with that individual?

What questions will you ask?

How will you ask the questions to facilitate information gathering and decrease the potential for defensiveness, paranoia, or increased anxiety, from the person with whom you are talking?

B. Observation

What, if anything, do you want to observe to increase your understanding of the problem or to give you ideas about alternatives for resolution?

C. Documents

What are the pertinent laws, regulations, or policies, that apply to this problem?

What other documents will add to your understanding of the problem or provide ideas regarding resolution?

Define the Problem to be Addressed

Review all of the information you have pertinent to the problem.

Have you been able to verify the complaint?

What seems to be the underlying issue? What is the root problem that must be addressed to obtain the outcome the resident wants?

Check back with the resident regarding the information you have and the problem to be addressed.

Notes:

MODULE VII

Equipping Long-Term Care Ombudsmen for Effective Advocacy:
A Basic Curriculum

THE PROBLEM-SOLVING PROCESS RESOLUTION

Curriculum Resource Material for Local Long-Term Care Ombudsmen

Developed by Sara S. Hunt, Consultant

National Long-Term Care
Ombudsman Resource Center
National Citizens' Coalition for Nursing Home Reform
1828 L Street, NW, Suite 801
Washington, DC 20036
Tel: (202)332-2275 Fax: (202)332-2949
E-mail: ombudcenter@nccnhr.org
Web Site: www.ltcombudsman.org

DECEMBER 2006

ACKNOWLEDGMENTS

Advisory Committee

Many thanks to the Advisory Committee for the Local Long-Term Care Ombudsman Curriculum—Esther Houser, Oklahoma State Long-Term Care Ombudsman (SLTCO); Linda Sadden, Louisiana SLTCO; Eileen Bennett, Long-Term Care Ombudsman Program (LTCOP) Manager, Montgomery County, Maryland; Gloria Simpson, Regional LTCO, Kansas; Heather Bruemmer, Ombudsman Services Supervisor, Wisconsin LTCOP; Sherry Culp, Director of Program and Services, Nursing Home Ombudsman Agency of the Bluegrass, Lexington, Kentucky, for their review, testing, and comments.

Documents from State Long-Term Care Ombudsman Programs

Much of the content in this module is adapted from the LTCOP manuals or modules developed by Sara Hunt for the following states, Louisiana, Alaska, and Illinois. The content also has sections adapted from the Oregon Long-Term Care Ombudsman Certification Manual, developed by Wayne Nelson and revised by Ann Fade, 2005.

ABOUT THE AUTHOR

Sara Hunt, MSSW, is a consultant for the National Long-Term Care Ombudsman Resource Center with expertise in the areas of ombudsman training, policy development, program management, and care planning and quality of life. Sara was the State Long-Term Care Ombudsman in Louisiana for five years (1981-1986) and has served as a consultant to the Ombudsman Resource Center since 1987. For more than twenty-five years, Sara has been developing and conducting training programs, most of those for ombudsmen. She is co-author of Nursing Homes: Getting Good Care There.

ABOUT THE PAPER

This curriculum module was supported, in part, by a grant, No. 90AM2690, from the Administration on Aging, Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not therefore necessarily represent official Administration on Aging policy.

Module VII: Problem-Solving
Part 2: Analysis, Planning, Resolution, Follow Up and Resources

OUTLINE

INTRODUCTION

The purpose of this module is to discuss:

- The ombudsman role in resolving problems.
- How to use the information gained during the ombudsman investigation to plan resolution strategies.
- The primary ombudsman approaches in resolving problems.
- The ombudsman responsibilities for follow-up after a resolution strategy has been attempted.

This module is a sequel to “The Problem-Solving Process Investigation” module. It covers Stages 2 and 3 of the problem-solving process. The information gathered during intake and investigation is analyzed and used to plan a resolution strategy. The long-term care ombudsman (LTCO) then acts to resolve the problem. If these actions are skipped, the ombudsman risks being ineffective in resolution.

Table 1: The Problem-Solving Process

Stage 1 Intake and Investigation	
Receive the Complaint	Receive problems, complaints, concerns.
Gather Information	Collect information from interviews, records, observations.
Identify the Underlying Problem	Review information gathered. Assess what seems to be at the root of the problem. The complaint may be only a symptom.
Stage 2 Analysis and Planning	
Analyze the Situation	Once you identify the problem, consider the causes.
Consider Solutions	Generate alternative solutions or approaches. Who should be involved? When? How? Why?
Identify Obstacles	Anticipate obstacles to help select an appropriate approach.
Stage 3 Resolution and Follow Up	
Choose an Approach	From your list of alternative solutions, choose the most efficient way to proceed, keeping any obstacles in mind. Identify alternative strategies in case you need them.
Act	Proceed with the selected plan, but be prepared to use an alternative.
Evaluate Outcome	Check back with the persons involved to evaluate the outcomes. Is the problem solved? Is it partially solved? If not, look for new approaches or information and start again.

Analysis and Planning

Once a complaint has been investigated, as a LTCO, you are ready to analyze the information you have gathered to determine the reason the problem occurred. The example of Mrs. Bronner's missing purse in the Investigation Module illustrated the importance of identifying the underlying problem of knowing why the problem occurred. This analytical process will enable you to more effectively plan resolution strategies by defining potential solutions and identifying obstacles that may be encountered.

Analysis and Planning is Stage 2 of the problem-solving process for LTCO. There are three steps in this stage of problem solving:

1. Analyze the situation
2. Identify the potential solutions
3. Identify potential obstacles

Analyze the Situation

Why did the problem occur?

The information gathered during your investigation should give you some idea about the cause of the problem. Your investigation may reveal that the underlying or root problem is not the one that was reported to you. For example, you may have been told that articles of clothing are being stolen. During your investigation, you learn that clothing is simply not being returned from the laundry room. Accurately determining the root problem is essential to finding a lasting solution.

Determining the root problem is essential to finding a lasting solution.

Thinking through the cause of the problem automatically leads to identifying potential solutions. Questions that might be considered are:

- Was there an oversight on the part of the facility staff?
- Was there deliberate retaliation against the resident?
- Is the problem related to policies/procedures of the facility?
- Are there communication problems or trust issues between the resident or relatives and staff?
- Is the facility habitually short staffed?
- Does the resident's physical or mental condition make good care extremely difficult to provide?
- Is the quality of care related to the resident's method of payment (e.g., Medicaid vs. private pay)?

What justification or explanation does the facility offer for the problem?

A thorough analysis includes the perspective of the facility. Some possible explanations the facility might give could also indicate obstacles to resolution. Examples of statements you might hear are:

- There is no problem.
- The problem is due to a "difficult" resident or family member.
- The facility's action is based on medical/professional judgment.
- The care is as good as it can be considering the low rate of reimbursement.
- The facility meets the regulations and has good inspection reports.

Who or what is at fault regarding the problem?

Determining who or what is responsible for the problem is important preparation for moving into the resolution stage. The responsibility may rest with one or more of the following:

- Facility staff failed to perform their duties properly.
- State/federal regulations are lax or confusing regarding the issue(s) raised by the complaint.
- Third-party reimbursement programs may not pay for certain procedures, services or items.
- Independent professionals (e.g., doctor, physical therapist) may not leave clear instructions for residents and staff to follow.
- The resident or family may be causing or contributing to the problem.

Identify Solutions

Use the information from your analysis of the situation to begin planning the next stage of the problem-solving process. Begin by identifying possible solutions to the problem. Keep the complainant's/resident's goals in mind.

- What does the resident want as an outcome?
- What might resolve the problem?
- What will it take to keep it from recurring?
- How many possible solutions can be identified?

Identify Obstacles

Once possible solutions are identified, you need to anticipate obstacles that might affect resolution. You do this by examining each potential solution and asking, “What obstacles might be encountered in seeking this outcome?”

Obviously, it does little good to identify potential obstacles without considering possible ways to overcome them. Using your list of potential obstacles, think of other alternatives to keep these obstacles from deterring a resolution. Remember that your list is not exhaustive, nor is it the only approach that will work. Sometimes there are several ways to resolve a problem. Just be prepared with ideas and remain flexible in order to prevent obstacles from ending a resolution discussion.

Table 2: Examples of Potential Obstacles and Solutions

Potential Solution	Potential Obstacles	Suggestions for Overcoming
Permanent assignment of staff	• The Director of Nursing resigns and the position is vacant for a long time • The rate of staff turnover is so high that permanent assignment is meaningless. • Staff and residents are not prepared for this change in staffing pattern. Without preparation and guidance, much resistance will be encountered.	• Identify and share resources on this topic, such as other facilities or best practice articles. • Encourage training and transition during change, promoting permanent assignment as a positive, use this in recruiting and retaining staff.
A revision in the resident's care plan	• There is no follow through with the changes. • The CNAs are not informed of the changes. • No one checks with the resident to see if the changes have the desired result. • The revision is made without the resident and family understanding the full impact.	• Advocate for a care plan that is clear, specific, and understood by all. • Ask how all pertinent staff will be informed and trained in the changes. • Be sure the resident knows who to contact if concerns arise.
Training staff to use a different approach	• The training is too theoretical and staff does not understand what they are to do. • There is no supervision or modeling of the change following the training. • Expectations of supervisors do not change to reflect the new approach.	• During resolution, get agreement on how training will be applied to daily staff routines and addressed in supervision. • Identify changes that can be observed as a result of the training.
A change in menu items and serving techniques	• The administrator says the change will cost too much. • The administrator says corporate headquarters will not approve such a change. • A dietary consultant with different expertise will be needed and the facility has an existing contract with someone else. • Staff resist when they are ordered to make changes without receiving an explanation, training, or support.	• Identify and share resources on this topic, such as other facilities, articles, and consultants. • Offer to support the administrator's request to the corporation for a change or to directly deal with the corporate office yourself. • Discuss the positive changes that everyone will experience as outcomes.

At this point, you have analyzed the information collected during your investigation, verified that there is a problem you can work on, identified what the root of the problem is – in other words, the problem that must be resolved – and thought of potential solutions, obstacles, and ways to overcome them. The next step is resolving the problem.

Ombudsmen always seek to resolve a problem to the satisfaction of the resident. However, achieving this goal is not always possible. Sometimes obtaining total satisfaction is limited due to factors such as a lack of resources, a change in the resident's condition, or the lack of specific regulatory language. Despite obstacles, on a national basis LTCO resolve a majority of complaints to the satisfaction or partial satisfaction of the resident or complainant. Ombudsmen take a complaint as far as possible to accomplish the desired outcome, follow-up with other agencies and the resident when a complaint is referred, and check back with the resident later if a complaint was withdrawn.

Ombudsman resolution actions can be classified and reported in one of six ways:

1. Requires policy, regulatory or legislative change to resolve
2. Not resolved
3. Withdrawn
4. No action needed or appropriate
5. Partially resolved
6. Resolved[1]

[1] The National Ombudsman Reporting System, October 2006, Administration on Aging.

Resolution

From the information gained in Stages 1 and 2 (see *Table 1: The Problem Solving Process*), you should be ready to choose an approach to resolve the complaint, act, and evaluate the outcome. Remember the potential obstacles identified in Stage 2, and be flexible enough to use a different approach if your initial choice does not achieve the expected results.

The important point is that the solution has to "fix" the problem.

Resolution simply means coming up with a solution. Sometimes you will develop a solution to try to "sell" to the respective parties; at other times, you may have to bring people together and help them work out the solutions that are meaningful. The important point is that the solution has to "fix" the problem. For example, helping a resident search for lost clothing may be a nice thing to do, but it does not provide a lasting solution to a problem of mishandling of laundry or personal possessions. On another case, you might have a charge nurse who agrees to let a resident stay up late tonight which is the resident's usual routine. To achieve a lasting solution, the resident's care plan might need to be revised or a note made on the resident's records about her preference for a later bed time. All night staff who work with this resident need to be notified about this change. Without these additional steps, a later bed time might be only a one night accomplishment; then you will have to deal with the same problem a second time.

It is important to recognize when a solution to a problem or an agreement has been reached. Some people become so involved in investigation or negotiation that they fail to realize that they have won their point or solved the problem. On the other hand, you should also recognize when a satisfactory solution has not been reached, and the problem continues to reoccur. When a satisfactory agreement has not been reached, it is time to discuss the problem with your LTCO supervisor or with the State Long-Term Care Ombudsman (SLTCO).

Stage 3 of the problem-solving process involves the following three major steps:

1. Choose an approach for resolution.
2. Act to resolve the complaint.
3. Evaluate the outcome.

Choose an Approach

Complaints may be resolved in many ways. Most are resolved at the facility level by simply bringing the problem to the attention of the staff or administrator in a polite manner. The obvious exception is when the resolution of a problem is beyond the facility's control, such as Medicaid's denial of a resident's application for a customized wheelchair. The Medicaid agency has to be involved in the resolution of this problem. However, there are other, more adversarial approaches that may be required when the complaint cannot be resolved at the facility level. These are discussed later in this chapter. To begin with, LTCO focus on the collaborative methods used for solving the complaint within the facility.

Practice Considerations

Remember to use the care planning process, resident councils, and family councils whenever appropriate to resolve problems. Although they are not all equally effective in all facilities and sometimes may not exist, especially family councils, all three of these can be effective avenues for communication and problem solving. Furthermore, whenever you use one of these, or support a resident in using one, you are modeling a way of working out issues within the facility.

Use care planning as a problem-solving vehicle to focus everyone's attention on the resident's needs, routines and preferences. Advocate for care plans that build on the resident's schedules and strengths.

Clarification of a law or legal advice might be needed in order to choose an approach and offer options to the resident. If you need this type of legal information, contact your LTCO supervisor or the State LTCO.

Ombudsmen are not regulators. A regulator looks for compliance with a standard or rule. A regulator can also demand conformity to a specification and can punish the care provider for any failure to comply.

The LTCO focuses on the residents. A LTCO has a much broader mandate and employs a wider range of options in resolving problems. A LTCO cannot punish to achieve compliance. In most cases, a LTCO brings problems to the caregiver's attention so that they can solve them before they get out of control and before a regulator must get involved.[2]

LTCO Behavior Style

The appropriate behavior style for LTCO is best characterized by the simple but important "Three F" principle.[3] The LTCO must be:

1. Fair.
2. Firm.
3. Friendly.

Strategies for Resolving the Problem in the Facility

As a person working on behalf of residents and their interests, you need to become familiar with a variety of techniques for resolving complaints. Some of these techniques are especially well suited for handling individual problems.

As you can see in Table 3: Resolution Strategies at Facility Level, there are three primary strategies for resolving complaints at the facility level:

1. Self-advocacy
2. Mediation
3. Negotiation.

Self-advocacy and resident empowerment are discussed more fully in the Residents' Rights module of this curriculum.

Long Term Care Ombudsmen rarely use true mediation because ombudsmen are not usually neutral; ombudsmen are resident advocates. The one situation in which true mediation may be used is with family members or with issues where one resident's rights conflict with that of other residents and the residents are equally able to participate. Resident to resident issues can be difficult. As a LTCO you seek to represent the rights of all residents. To help you think through your role in working with resident to resident issues, refer to "Program Guidance: Working With Residents With Opposing Views," in the appendix.

You can negotiate <u>how</u> a resident's right will be met, not <u>if</u> it will be met.

Of these three, negotiation is the strategy you probably will use most frequently. However, it is important to remember that you can negotiate processes -- the how and when something will be accomplished -- but you cannot "give up" the outcome if it is a matter of law and regulation. As an ombudsman, you can negotiate <u>how</u> a resident's right will be met, not <u>if</u> it will be met.

Table 3: Resolution Strategies At Facility Level

SELF ADVOCACY
Urge complainants to take action themselves. When people are able to resolve their own problems, they become more confident and less dependent. This gives power to the complainant. It is an empowerment strategy. 1. An excellent way to encourage self-advocacy is to help residents' voice concerns and resolve problems through the resident council. In some facilities, resident councils have been very effective in relating opinions and feelings to administrators, resulting in changes in the facility. In other homes, the resident council may be little more than an alternative activity to bingo. The more independent the council is of staff involvement, the more likely it is to be useful in solving problems. You will have to evaluate each council to determine whether it is an appropriate forum for resolving complaints. 2. A resident might agree to directly participate in resolution if you agree to take the lead in the meeting or at least to be present for moral support. 3. Families can use family councils to help resolve problems.
MEDIATION
Try to get the complainant and the appropriate facility personnel to meet and develop a mutually agreeable solution. The role of the mediator can be difficult since both parties sometimes use the mediator as a target for their bad feelings. In some cases, the parties may have different goals. In other cases, both parties may agree on the goals but disagree on how to reach them. 1. A mediator is essentially a facilitator; trying to encourage open communication and helping both sides find as much common ground as possible. 2. A mediator is neutral, establishing the "ground rules" for the meeting but not taking sides. 3. Mediation is appropriate when the parties involved have equal power.

NEGOTIATION

In negotiation, you bargain with another party to arrive at a binding agreement. Negotiation can avoid confrontation with the other party by clarifying the consequences of a continued course of action.

1. Negotiating in a long-term care facility will generally occur with the administrator or home operator.

2. In negotiations, it is critical for you to know:
   a) Whom you are representing.
   b) What problems you want to solve.
   c) What may be acceptable solutions.

3. Negotiations should not be entered into without knowing what can and cannot be done by all parties to achieve the desired results.

4. When you plan to negotiate in a formal session, take the following actions.
   a) Prepare an agenda so that you are not sidetracked from the items you want to discuss.
   b) Ask for a timetable if the facility spokesperson promises that certain things will be done.
   c) Ask for a written agreement if the solution to a problem involves a major change in facility policy or is dependent on promises made by the facility.
   d) Summarize the results following any formal session with a letter.
   e) Monitor “agreed-to” actions resulting from the session to ensure that changes are made.

Principled Negotiation

The strategy of principled negotiation was developed a few years ago by a group called the Harvard Negotiating Project. This strategy is outlined in a book entitled, "*Getting to Yes*." The book is an excellent resource for ombudsmen.

The general principle is to bargain on interests rather than positions. The traditional method of negotiation involves each side taking a position, arguing its merits, and reaching a compromise. Unfortunately, compromises are often difficult to find and may leave both parties less than satisfied.

Following are the key elements of principled negotiation.

1. Define the problem and negotiate on the merits.
    a. Recognize that the participants are problem solvers.
    b. Concentrate on achieving a wise outcome reached efficiently and amicably. To do this, you must:
        (i) Focus on solving the problem.
        (ii) Outline how the problem hurts both parties' interests.
        (iii) Refrain from trying to score debate points or outsmart the other party.

    Example:

    LTCO to Laundry Supervisor: "You do have a huge responsibility and it is difficult to please everyone. However, having residents receive clothes that don't belong to them is a problem. Can we take some time and think about how it might be solved?"

2. Separate the people from the problem.
    a. Be soft on the people, hard on the problem.
    b. Proceed independent of trust. Achieving resolution is based on interests and results, not on personal relationships.
    c. Be aware that the other person probably perceives the situation differently than you do.
    d. Do not react to emotional outbursts. Let the other side let off steam.
    e. Phrase your proposals in terms of what you think will solve a problem, not in terms of what they should do.

Example:

LTCO to the Director of Nursing: “I can see that discussing meal trays being served to residents, then removed without the resident being assisted with eating, is upsetting you. Let’s focus on ways to avoid this in the future. It might help if the resident assistants were clear about which residents need assistance with eating and drinking, whose responsibility it is to assist with eating, and how to do this.”

3. Focus on interests, not positions.
    a. Explore interests.
    b. Realize that each side has multiple interests.
        i. Try to find compatible interests that can form the basis of a solution. Identify any areas where the resident’s interests are compatible with the facility’s stated interests.
        ii. Be able to professionally explain how the resident’s interests might be in conflict with the stated interest of the facility, if necessary.
        iii. Don’t blame the facility’s interest-orientation as the cause of the problem.
    c. Avoid having a bottom line.

Example:

LTCO to Administrator: “I know this facility’s mission is to be a home-like place where the care is good. Let’s discuss what one specific resident, Mrs. Quiet, needs in order to feel at home and be comfortable with her care routine.”

4. Invent options for mutual gain.

    a. Develop multiple options to choose from; decide later.
    b. Look for solutions that will allow both sides to gain something, in contrast to compromises where both sides lose something.
    c. Do not be wedded to a single solution. There is almost never a single answer to a problem.
    d. Try to develop a win-win solution based on shared interest.

    Example:

    LTCO to Administrator: “Based on our discussion, we both agree that Mr. Dillard needs more opportunities for movement and to be outdoors. Let’s brainstorm some ideas about how his needs can be met while complying with the safety and supervision requirements for this facility.”

5. Insist on using objective criteria.

    a. Try to reach a solution based on standards independent of will, such as laws, written rules, and/or outside experts.
    b. Reason and be open to reason; yield to principle, not pressure.

    Example:

    LTCO to Director of Nursing: “I understand your concern that Mrs. Evert’s health will rapidly decline if she doesn’t agree to take the medicine her doctor ordered. You’ve done an excellent job of fully explaining the consequences of her decision and offering other options. Nevertheless, residents have the legal right to refuse treatment.”

Sources of Power in Negotiating

In addition to practicing the techniques of principled negotiation, you should be aware of the sources of power that are available to you as an ombudsman in resolving conflicts in the long term care system. Your base of power in negotiation includes: [4]

- *The Older Americans Act:* The law requires every state to establish a Long Term Care Ombudsman Program to resolve complaints on behalf of facility residents.
- *Standards of Care*: Federal and state regulations establish a standard of care by which facilities must abide. In your advocacy, you seek adherence to these standards.
- *Civil Law:* Legal avenues exist by which a facility can be held accountable for violations of civil law. You offer the opportunity for the facility to avoid unpleasant legal conflicts by working out an agreement.
- *The Public Interest:* You represent the concern of the public at large for high-quality nursing facilities and assisted living homes.
- *Facility Reputation:* The facility's willingness and desire to resolve problems and to cooperate with you can enhance its good name.
- *Resolution:* You can provide assistance in resolving problems of mutual concern.
- *Necessity:* If the problem has persisted to such an extent that you are called into the situation, then that problem is not likely to go away without some type of outside intervention.
- *Persistence:* You are charged by the LTCO statute to work for resolution. In accordance with that mandate, you will stay with the situation until it improves.
- *Best Alternatives:* You offer the opportunity for an "in-house" resolution. If a problem cannot be resolved at this level, you must refer the problem to the SLTCO who will likely seek regulatory action.

- *Brainstorming:* If a problem persists, it is in the best interest of everyone involved that it be resolved. As the saying goes, two heads are better than one. By meeting, you can think of a workable solution.

- *Linkage with Community Resources:* If resolution requires outside assistance, you can play a key role in tapping needed community resources and bringing them into the situation.

Adversarial Strategies

If a complaint cannot be resolved at the facility level, it may be necessary to use adversarial strategies to correct the problem. These strategies include involving regulatory agencies, the community, courts, legislature, and the network of agencies serving the elderly; and in very rare cases, the local media.

As a rule of thumb, remember that the more adversarial your method, the greater your burden of proof. You must have very good quantity and quality of evidence before seeking resolution through one of these strategies.

Also remember that you are no longer working in cooperation with the facility. There will likely be some damage, at least temporarily, to your working relationship when more adversarial methods are used. However, there may be some instances where these methods are the only way to resolve the problem.

The more adversarial your method, the greater your burden of proof.

Warning and Referral

When LTCO efforts to resolve problems at the facility level fail, the LTCO may offer a warning of intent to refer a problem or make an actual referral. Warning of intent to refer is a second-to-the-last resort in the LTCO bag of tricks and is not a process that LTCO engage in lightly. Sometimes when LTCO try to explain to facility management the consequences of further inattentiveness to an ongoing problem, it is perceived as a threat. It is not. A warning is a form of counsel and is in a very real sense a courtesy insofar as it is a notice offered prior to the actual referral. It is nothing more than a notice of possible consequences.

A warning can get the attention of the offending party. It can differentiate very important from less important issues. It can clarify the extent of one's commitment to a problem. It can help define the power relationship between parties. But a warning can only be productive and constructive if the party to which it is issued believes that it is credible.

To be credible, the receiving party must believe that the LTCO will follow through with the steps described in the warning, that the regulator would be likely to find the facility out of compliance, and that the process and/or outcome is something to avoid.

The bottom line, then, is that a LTCO never expresses a warning unless fully intending to carry it out. LTCO should never issue a warning unless it is absolutely necessary. There is no greater danger than in the overuse of warnings. LTCO who have not fully developed their skills in problem-solving techniques often resort unnecessarily to warnings. In time, this will prevent the LTCO from developing a good working relationship with providers. On the other hand, a judiciously issued fair warning can be a constructive way to develop program credibility. **Until you are an experienced LTCO, check with your LTCO supervisor before concluding that nothing else can be done to resolve the problem with the facility and that a warning of additional steps is required.**

Referral to Another Agency

The most commonly used adversarial strategy is referral to the state's licensing and certification agencies. For this kind of referral, you will need to provide detailed information and have the permission of the resident(s). The more detailed a complaint is, the better the chance that it will be verified by the regulatory agency and eventually resolved. If there is evidence of a trend at the facility, it should be included in the complaint so that the investigators can be alert to more widespread problems in the facility. Follow the policies of your LTCOP in making a referral to one of these agencies. Asking another LTCO to read your referral before it is sent is a good practice to ensure that what you have written is clear to someone who is not familiar with the situation.

It is also useful to become acquainted with employees of these agencies in your area so that problems may be discussed in an informal manner. Creating and maintaining such a relationship offers the possibility of a two-fold benefit. First, frequent contact with the agency may serve as a form of subtle pressure, which can lead to a more responsive bureaucracy and therefore to an improved regulatory system. Second, once such a relationship has been established, you can gain information about the regulatory perspective through informal contact.

If the facility is unyielding, LTCO need to be resourceful in identifying other places to go in order to achieve resolution on behalf of a resident. Other agencies or offices where LTCO sometimes refer complaints include public health departments, the Fire Marshall, Medicaid Fraud and Abuse, public guardianship office, and courts with applicable jurisdiction.

Referral to Media

This is the most rarely used tactic by LTCO to address problems. While LTCO may be approached by the press concerning long-term care issues, the LTCOP rarely initiates a news story focusing on a problem. If you are contacted by the media, you must follow the federal LTCOP confidentiality and release of LTCOP information provisions as well as the policies of your state's LTCOP.

Generally, referring a problem to the media would require that the following criteria be met:

1. All attempts at problem resolution by all levels of program staff (including the SLTCO) have been attempted, documented and have not produced desired results.

2. Taking the problem to the media will not reveal the identity of any resident without the resident's permission.

3. The LTCOP, local and state, has carefully considered the consequences, intended and potentially unintended, to residents, family members, and to the LTCOP.

4. Facility administration is uncooperative or incapable of affecting a resolution.

5. The problem is serious enough to warrant media attention and public concern.

6. The system has generally failed to correct the condition and no alternative steps to solution are available.

7. The SLTCO has been informed of the intent to go to the media and has approved such action or is carrying such action forward.

Litigation

Another possible remedy for residents whose legal rights have been violated is referral to an attorney. Ombudsmen can assist residents to get in touch with locally available legal services for seniors. Going to an attorney is a resident's option and should not be pursued by a LTCO except in accordance with SLTCOP policies or guidance.

Check with the Resident

To recap, you have investigated and verified the complaint, identified the underlying problem, identified potential solutions, obstacles, and appropriate resolution strategies. Before you act to resolve the complaint, check back with the resident!

The reasons for this pause in your resolution work are to:

- Share with the resident what you've learned.
- Be sure the resident wants to resolve the problem.
- Verify the outcome the resident is seeking.
- Discuss ideas regarding how to resolve the problem (your ideas as well as any ideas the resident has).
- Encourage the resident to participate in the resolution process.
- Discuss potential ramifications to the resident, if any.
- Discuss potential outcomes and what might be gained, checking for any flexibility in terms of what will be satisfactory to the resident.

If you by-pass this step, you risk solving the "wrong" problem, proceeding when the resident wants to withdraw the complaint, and taking control and decision-making away from the resident.

Act to Resolve the Complaint

Once you have chosen an approach and checked with the resident, you act to resolve the complaint. You implement your plan, keeping other options in mind if your initial strategy does not achieve the desired results. There are numerous skills that will be helpful in the actual resolution process. Most of these were discussed in previous sections of this module. Two more skills are presented here: earning trust and dealing with authority figures. Remember, a LTCO always seeks to be "fair, firm, and friendly".

Confronting Authority Figures

Many of us have difficulty confronting authority figures in our daily lives. An authority figure could be any of the following: the head of an agency, an elected or appointed official, a facility administrator or owner, or anyone who is in a position to hurt or help you or your clients. You, too, may be perceived as an authority figure because of your knowledge, experience, status, training, and/or position.

In resolving complaints, you will find yourself in a position where confronting authority figures are essential to achieve the results you seek. You must choose an appropriate approach toward a person who is perceived by others to be an authority figure.

Reactions to Authority Figures

Three common reactions to those who have the power to influence outcomes are*: avoidance, awe, and anger.*

Avoidance It may take weeks or months for agencies to process complaints or for courts to process cases; yet many persons immediately seek such remedies without first confronting the person directly responsible for the problem. Why? Because they think it will not work, dread failure, and dislike face-to-face confrontation, especially on someone else's "turf."

Awe Ironically, many persons may gripe about officials and corrupt politicians in private but cannot always be counted on to put their grievances in writing or to stand up at a public hearing. Many people are easily intimidated by a gavel or even an imposing tone of voice. Ombudsmen, too, can be seduced into a "cozy" relationship with the opposition. Certain professionals, such as doctors, have an aura about them that is difficult to dispel.

Anger It is frustrating to deal with officials or staff who fail to share your viewpoint. Some may even attempt to disguise their self-interest as concern for residents. Having to confront such persons on a regular basis can be quite stressful and may lead to anger or "burnout." Creative brainstorming and problem-solving sessions are a necessity in such circumstances, not a luxury.

Tips for Dealing with Authority Figures

- Make an objective assessment of the individual to find out if he/she will be an ally or an adversary.
- Size up the prejudices, preferences, and decision-making patterns exhibited by the authority figure, and study his/her overt and covert influence.
- Be aware of the appeal process and the chain of command if a person in authority renders an unfavorable decision.
- Be aware of the policies, guidelines, rules, regulations, and laws that govern the authority figure, as well as those he/she is in charge of or can control.
- Encourage those in positions of responsibility to fulfill their public trust. This is the most powerful approach. If you can show an administrator a resident's rights in black and white as stated in standards or statutes, there is a good chance that he/she will capitulate or be won over. The law is a very powerful tool that the ombudsman must know and call upon.

Building Trust

You cannot resolve a complaint unless residents, staff, and administrators trust you. This means you must maintain confidence, be respectful, and have a good attitude. Other specific techniques for earning trust are summarized below in *Table 4: Techniques for Building Trust.*

Table 4: Techniques for Building Trust

DO	DO NOT
• Start with the assumption that the other person wants to provide good care and make the residents happy. • Be professional in your relationship, words, voice tone, and nonverbal communication such as posture, facial expressions, eye contact, and gestures. • Give providers clear reasons to change their minds—reasons that are important to them. • Show how the changes will benefit the residents as well as the providers. • Be prepared with examples of how other facilities have benefited from similar changes, if applicable. • Hear exactly what is being said. • Allow the provider to contribute to the resolution, identify actions, and make decisions. • Restate to clarify and show understanding. • Have a backup plan and other alternatives in mind in case the provider does not identify an appropriate plan for resolution. • Know the applicable laws, regulations, or standards, in case you have to use these to reach a resolution. • Stick to the outcome that the resident wants without being sidetracked on other issues. • Be assertive in seeking resolution. • Be unyielding on points that clearly violate laws or regulations. • Persist in seeking resolution. If the provider refuses to agree to an acceptable resolution, know what your next step will be and inform the provider. • Seek a clear statement of resolution actions that will enable everyone to know when the actions have been completed. • Set a time for follow-up to see if the resolution achieved the desired outcome.	• Make the provider (person with the power to change things) feel defensive. • Evaluate, make value judgments, accuse, or indoctrinate. • Appear judgmental in your posture or facial expressions. • Put the provider in a passive position of having to say, “Yes” or “No,” to the solutions you have identified. • Be demanding, threatening, intimidating, or aggressive. • Negotiate away any resident’s rights. • Negotiate about a provider’s responsibilities to maintain compliance with the law or regulations. • Bluff or develop your own interpretation of a law or regulation that will not be supported by a regulatory agency. • Become defensive or take things personally even if they are intended that way. • Lose sight of the goal you are seeking on behalf of the resident

PEP Method: Point, Evidence, Repeat Point[5]

A proven way to reach resolution that works in many types of situations is the Point, Evidence, repeat Point (PEP) method. This method uses the communication skills and problem-solving approaches that been discussed throughout the curriculum modules. PEP is focused, direct, respectful of the other person, and allows you to be the resident's advocate.

1. Get Your Message across.
    a) Give your clear statement of the problem.
    b) Present the evidence you have gathered during your investigation, starting with the most persuasive evidence.
    c) Restate your statement of the problem.

2. Receive Feedback
    a) Listen attentively and reflectively.
    b) Do not interrupt.
    c) Do not argue.
    d) Find areas of agreement to incorporate into your argument.
    e) If the other person responds with defensiveness, it could mean they did not really hear your message or that it was not clearly presented.

3. Repeat the Process: Persistence is the key. It may take 3 – 10 times through this process to change the other's behavior. Tips:
    a) Do not back the other person into a corner.
    b) Allow the other person to retain his or her dignity.
    c) Make sure the solutions meet the resident's needs.
    d) Do not insist that they be cheerful about addressing the problem. You are asking for changed behavior.
    e) Arrange a time when you will check back with each other to make sure the solution is working.
    f) Express appreciation.

[5] This section and the following section are from *The Ombudsman Training Manual*, Oregon LTCOP, developed by Wayne Nelson, April 1992, and revised by Ann Fade, 2005.

4. Formulate an Action Plan: The only way you can be sure that your advocacy has had an effect is if you and the other person can agree on an action plan.

a) How will the problem be solved?
b) Who is responsible for making sure the plan is implemented?
c) When will the plan be implemented?

5. Monitor the Implementation of the Action Plan.

a) Make sure the resident is satisfied with the action plan.
b) Keep checking with the resident to make sure the changes are being made.
c) Make contact with staff responsible for implementation.

Example of PEP Method

Ombudsman	
Point	Mrs. Rodriguez needs another set of dentures because the ones she had when she was admitted have been lost.
Evidence	• The charge nurse, Mrs. Downs, says the staff have looked for the dentures, but cannot find them. • Her daughter, Mrs. Lopez, filled out a grievance form two months ago when the dentures were first missing, but so far, nothing has been done to replace them. Mrs. Lopez says the last time she saw the dentures was when a staff person was taking them out of the room to clean them.
Repeat Point	Therefore, Mrs. Rodriguez needs replacement dentures
Administrator	
Point	I resent your implication that we have been neglecting Mrs. Rodriguez in any way. I believe it is her fault the dentures are missing. I think she either hid the dentures in her sheets or crumpled them in a napkin because she has done that with other items. We cannot be responsible for things that residents intentionally misplace.
Ombudsman	
Point	I know you are concerned with providing good resident care, and it is clear that Mrs. Rodriguez needs new dentures.
Evidence	• Your staff has not been able to locate the dentures. • They've been missing for two months, and the last time they were seen, they were in the possession of a staff person. • Mrs. Rodriguez could not independently remove them from the area of her bed.
Repeat Point	Mrs. Rodriguez needs new dentures because it is a point of dignity for her and because not having them is affecting her ability to eat when she wants.
Administrator	
	Listen, I don't wan a big fight over this. I don't believe we're legally obligated to get her new dentures. But because so much time has gone by, I'll make an exception to this once.
Ombudsman	
	Thank you. I know Mrs. Rodriguez and her daughter will be pleased with your decision.

Summary of Steps in Preparing for a Resolution Meeting

1. Trust your credibility.
    a) Advocacy: You are the resident's champion.
    b) Bottom Line: Your effectiveness depends on persuasiveness.

2. Get ready.
    a) Investigate first.
    b) Present facts.
    c) Rehearse.
    d) Know what the resident, and you, want.
    e) Write your case. This diffuses feelings and builds your confidence. Make it to-the-point, brief, non-blameful.
    f) Practice.
    g) Anticipate objections and have answers for them.

3. Practice your presentation skills.
    a) Visualize the meeting and what you will do and say.
    b) Be professional.
    c) Select the time and place.
    d) Be consistent in conveying the message correctly, both verbally and nonverbally. How the message is sent is as important as the words.
        i. Be aware of your body language: eye contact, facial expression, gestures, voice tone, breath.
        ii. Use assertive language rather then submissive or aggressive language.

Evaluate the Outcome

Once you have implemented a solution to a problem, you must evaluate the outcome to see whether it was actually resolved. This requires checking back with the persons involved to see whether the problem has been resolved to their satisfaction. The purpose of follow-up is to verify that resolution of the complaint has occurred and evaluate your effectiveness.

Complaints should be followed up at one or two regular intervals. This may range from a few days to several months after resolution, depending on the nature of the complaint. If the problem is recurring, or the agreed-upon solution was not put into effect, it may be necessary to reopen the investigation. At this point, you should determine what went wrong and take further action. If the complaint resolution has been successful and the case remains closed, you can elicit feedback about the process and outcome from the complainant.

There are two factors you should keep in mind while attempting to resolve a complaint:

1. Some complaints cannot be resolved. This can happen in spite of a thorough investigation, unquestionable verification, and a wise and persistent course of action during the resolution process.

2. Complaint resolution is not always clear cut.
    a) In some cases, a problem will go away, and then reappear.
    b) In other situations, some parts of the problem will be taken care of, but not others.
    c) In some instances, the complainant will not be completely convinced that the situation is as good as it should be. At other times, the complainant will say that everything has been solved, regardless of your desire to pursue the matter further
    d) Most cases become less “black and white” the more they are examined; so it is possible that you will handle many cases that you can call only partially resolved.

Resolution in Assisted Living Facilities

Although the problem solving skills and approaches that have been discussed are generic to LTCO work in all settings, some adaptations may be necessary when working in assisted living facilities. Such facilities have fewer regulations and different staff and resident dynamics than nursing facilities. An excellent resource to assist you in adapting the problem-solving process to these types of facilities is, “Translating Nursing Home Ombudsman Skills to Assisted Living: Something Old, Something New,” by Robyn Grant. You can get this resource from the National Long-Term Care Ombudsman Resource Center or by download at: http://ltcombudsman.org/ombpublic/251_1340_1340_8674.cfm.

COMMUNITY RESOURCES AND SUPPORT SYSTEMS

You may frequently encounter problems that require services that you, as an ombudsman, cannot provide, or that require knowledge you do not have. You need to be aware of the state and local community resources and support systems that are available to meet residents' needs in these areas. A few such resources and systems are discussed in this section. Every state has additional resources that are not contained in this module. Consider this information as a beginning point in your list of resources.

Because the names and locations of some of these resources vary from state to state, you need to identify the equivalent resource in your state and any regional or local counterparts in your service area. A few of the key resources in your state are listed on the National Ombudsman Resource Center's website at:

http://ltcombudsman.org/static_pages/help.cfm.

Just click on your state and a list will appear with information about various agencies as well as a list of the regional ombudsman programs in your state. This link is a good reference if you need to contact a LTCO or agency in another state while you are working on a complaint case or need to give a family member contact information for a LTCO in another state.

The State Agencies on Aging

The State Agency on Aging provides various services to the elderly. As an ombudsman, you should make a point to familiarize yourself with the programs provided by this agency. It is charged with planning, advocacy, grant making and administration, and inter-agency coordination on elders' issues.

Adult Protective Services (APS)

Adult protective services programs respond to reports of abuse or neglect of persons aged 18 or older who cannot protect themselves because of physical or mental impairment. APS acts to prevent, remedy, or halt abuse or neglect while helping the adult maintain the maximum possible degree of personal freedom, dignity and self-determination. In some states, APS serves elders regardless of the setting. In other states, APS serves only elders who are not living in nursing facilities. You need to know who is served by the program in your state and when and how to make referrals to APS as a LTCO.

Insurance Counseling Program

The Insurance Counseling Program is located in different structures and has different names from state to state. In all states, this program answers questions about health and long term care insurance, Medigap policies, and Medicaid and Medicare benefits.

Legal Services

Legal assistance for the elderly may be provided by a number of sources: private attorneys, legal services programs, and the agency for protection and advocacy, whose name differs from state to state. Eligibility may be based on the type of problem, income, or other factors. The type of help available will also vary ranging from legal advice to actual representation in a suit against a facility.

Community Mental Health Centers

These centers may provide a variety of services to residents and their families. The level of services appears to vary greatly from place to place. Some centers have regular programs to provide counseling or treatment to residents. In other areas, assistance may come only on the basis of a direct request from a resident or family member or the center may not serve individuals living in nursing facilities. You should contact the local mental health center in your area to find out what services they provide.

Civic Groups

Virtually all the popular civic and business organizations have community service programs that include some type of assistance to elders. Some have specific projects that work to purchase wheelchairs, eyeglasses, or other items needed by nursing homes residents but not always covered by Medicare or Medicaid.

Church and Religious Groups

These groups may provide assistance in two important ways. First, many such groups visit facilities on a regular basis, assist with activities, and generally provide a positive presence in the home. Second, they often can provide spiritual counseling for residents. As a LTCO, you should take care not to impose your own religious beliefs on a resident; however, it is always appropriate for you to refer someone who expresses concerns in this area.

Other Organizations

The American Dental Association encourages its members to provide free engraving of dentures for the elderly. Your local dental association can tell you if this service is available in your area.

Support groups exist for individuals and families affected by a variety of diseases. For example, the Alzheimer's Association has local chapters in many areas. These groups may be valuable sources of information or assistance. In recent years, this association has developed a series of practice recommendations and training programs applicable to nursing facilities and assisted living facilities. For more information about this disease or these resources, go to their website:
www.alz.org or http://alz.org/qualitycare/dementia_care_pract.asp for the care resources.

Resource for Mentally and Developmentally Disabled Residents

You will encounter a number of residents with mental or physical disabilities. Although some residents will be older, many will be younger, disabled persons. Protection and advocacy services provide legal counsel on voluntary and involuntary admission and/or commitment to treatment facilities, legal capacity, change of status, transfer, discharge, and enforcement and protection of the rights of developmentally disabled and mentally ill persons. This agency can be called on when problems dealing with these issues arise.
In Arizona, the P & A is the Arizona Center for Disability Law.

Alternatives to Nursing Homes

You will encounter residents who want to leave the nursing home. Although many of these persons will need nursing home services and have no other place to receive such care, many residents do improve to the point that they are capable of living in alternative housing for elders. States are rapidly increasing home and community based services in order to keep individuals in the community longer. You should be familiar with the alternatives that are available in your community. These may include: adult day care, independent living apartments, congregate housing, assisted living facilities, and continuing-care retirement centers. Knowing the general eligibility requirements for these alternative services is important.

WHAT AN ADVOCATE SHOULD KNOW[6]

A good advocate must be knowledgeable about long-term care facilities, conditions, and issues. There is no substitute for current, factual information to support your advocacy efforts. A good advocate knows the following information.

Facilities in the Immediate Community

−What kind of facilities are they? What level of care do they provide? Do they participate in Medicaid or Medicare programs?

− Who lives there? The very old and very ill? Young people? Mentally ill? Disabled? How many beds does each facility have?

− What kinds of special programs does the facility offer? Rehabilitation? Community interaction? Physical therapy? Mental health services? Resident council? Family council? Does the facility provide the services that it advertises in brochures, telephone books, and the newspaper?

− Does the facility have a dementia special care unit? If so, what makes the unit “special”?

− What is the general atmosphere of the facility? Warm, friendly, active? Cold, quiet, sterile?

− Which facilities offer special model programs that could be duplicated by others?

− Which facilities encourage the public to visit and help?

− What kind of training is provided for the nursing assistants? How are the working conditions for workers?

−How does the facility measure up in meeting standards? What do inspection reports say about conditions?

[6]Adapted from materials produced by the National Citizens’ Coalition for Nursing Home Reform.

Regulations for Facilities

-What are the regulations and state licensure standards for nursing homes and assisted living facilities?

Regulatory Agencies

-What state agencies have jurisdiction over facilities, e.g., licensing and certification?

The Difference between Medicare and Medicaid programs

-What benefits do they offer?
-What types of facilities do they certify?

Who Makes Decisions about Facilities in Your Community

-Who owns the nursing homes and the assisted living facilities? Are doctors, legislators, or others involved in ownership?

-Are there “chain” facilities in your community? Where is the “home” office of the chain?

-Who is on the governing board of the nursing home? This information should be available from the Health Facilities Licensing and Certification.

-Is the administrator the owner or part owner? Does the owner own several nursing homes?

-Are there any independent citizens’ groups working on nursing home or assisted living issues in your community? Can they provide volunteer services or support?

Your Community Resources

- Who provides mental health services to residents in long term care facilities?
- What alternatives to institutionalization exist in your area? Are there waiting lists for such programs or services?

WORKING TO CHANGE THE SYSTEM: THE LARGER LTCO ROLE

Although the major day-to-day job of the LTCO is to resolve individual problems, it is important that you have some knowledge of the broader issues that affect facilities and the long term care system in general.

Achieving Long Range Goals

An important part of your work as an ombudsman is to achieve long-range goals for improving the system. There are several reasons that efforts directed toward long-range changes in the system are important.

- Improved care for all residents is a major reason why the ombudsman program was created. Issue work is work that allows an ombudsman the opportunity to work for all residents, not just the relatively small number of people who register complaints.

- Solving individual problems, while important, is often a “band-aid approach” to dealing with the inadequacies of the long term care system. An ombudsman can become so busy putting out brush fires that there is never enough time to plan how to fight the big battles.

- Working on issues can at times be more satisfying. This is not to say that the individual’s problem should be put aside in favor of a “fun project,” or that resolving an individual case is not satisfying. Working exclusively on individual cases can be frustrating, however, because it often does not allow time to step back and take a look at the larger picture. When too many individual cases are piled on top of one another, an ombudsman can feel weighed down and be more susceptible to “burnout.”

As discussed earlier, you will encounter repeat complaints in some facilities as well as similar complaints that recur in many different homes. Such systemic or repetitive problems may indicate a need to seek improved state legislation or enforcement of existing legislation, or to pursue other remedies that appear likely to protect the rights of all residents. It is important that you identify issues that are affecting all residents and consider steps that can be taken to change the system for the benefit of all residents.

Advocacy

Advocacy means using your voice on behalf of some person(s) in favor of some cause.

Your roles in solving individual problems include those of investigator, mediator, and negotiator. In working on system issues, you are fulfilling the role of ombudsman as advocate. It is a process by which you seek to influence those who make decisions to do so in ways that improve the quality of life and care for all residents.

The skills you use as an issues advocate are much like those you use to solve complaints. You must be able to gather facts and information and to plan and carry out actions.

You will need to think of creative ways to involve social services agencies, assembly or council representatives, state and federal legislators, the medical community, the legal community, and the business community.

Once other individuals and groups are involved, their interest in solving problems in long term care facilities should increase. With this interest developed, powerful individuals can be called upon to intervene when problems arise. Furthermore, the very fact of this interest will tend to keep facilities on “good behavior.”

A law is only as good as its enforcement.

Legislation is sometimes the most effective way of addressing problems in long term care facilities. Although effective laws can occasionally be adopted quickly and quietly, major reform legislation requires a great deal of organizing. Much effort is required and several months or years will pass, from the first steps of drafting major legislation until it is signed into law and then fully implemented by promulgating rules. Remember that any law is only as good as its enforcement.

Ombudsmen cannot get legislation adopted by working alone. Coalitions need to be formed to bring together as much support as possible. Organization in the community among senior citizen groups, unions, churches, social service providers, and consumer organizations will help demonstrate to the legislature that there is citizen support for a legislative initiative. Nursing home operators and their associations have a great deal of

political influence. This power must be understood and sometimes countered before laws that benefit nursing home residents become reality.

Such groups and coalitions have helped to enact the state laws on ombudsman access and residents' rights. Organizations such as the AARP are involved in working for improvements in the quality of nursing home care.

The Nursing Home Reform Amendments of 1987 is perhaps the most sweeping change in nursing home regulation history.

On the national level, the National Citizens' Coalition for Nursing Home Reform, located in Washington, D.C., is an extremely effective voice for residents. NCCNHR, as it is commonly known, is made up of residents, advocates, concerned citizens, LTCO, and others who share a desire to improve nursing homes. This organization is primarily responsible for organizing the coalition including nursing home associations, health care professionals, unions, consumer groups, and many others that lobbied Congress to enact the Nursing Home Reform Amendments of 1987. This piece of legislation is perhaps the most sweeping change in nursing home regulation in history**.**

Ombudsmen should be aware that they are part of a network of advocates and stay informed about state and national issues that affect long-term care residents.

APPENDIX

The Problem-Solving Process: Resolution Guidelines for Practice
Program Guidance: Working with Residents with Opposing Views

THE PROBLEM-SOLVING PROCESS:
RESOLUTION GUIDELINES FOR PRACTICE
Developed by Sara S. Hunt, Consultant

A Quick Reference for Problem Solving

The following list of questions is a “ready-reference” to use in thinking through issues and how to proceed. This list is a continuation of “The Problem-Solving Process: Investigation Guidelines for Practice,” contained in the Investigation module of this curriculum. It is not a comprehensive list nor is it rigid in its order of steps. It’s a guide to help clarify thinking and to ensure that you haven’t overlooked a key part of the problem-solving process. As previously mentioned, there will be times when problems can be quickly addressed. Resolving problems will not always require such a detailed analysis and resolution process as the following includes.

You can also use this reference to guide your conversations with residents and family members who turn to you for advice regarding working through issues on their own.

Stage 2: Analysis and Planning

Analysis

Why did the problem occur?

- Was there an oversight on the part of the facility staff?
- Was there deliberate retaliation against the resident?
- Is the problem related to policies or procedures of the facility?
- Are there communication problems or trust issues between the resident/relatives and staff?
- Is the facility habitually short-staffed?
- Does the resident's physical/mental condition make good care extremely difficult to provide?
- Is the quality of care related to the resident's method of payment, e.g., Medicaid vs. private pay?

What justification or explanation does the facility offer for the problem?

- There is no problem.
- The problem is the resident or the resident's family member.
- We are doing all that the regulations require.
- What the resident wants is beyond the terms of our contract or licensure requirements.
- We aren't paid enough to offer that type of service.

Who or what is responsible for the problem?

- o Facility staff failed to perform their duties properly.
- o State/federal regulations are lax or confusing regarding the issue(s) raised by the complaint.
- o Third-party reimbursement programs may not pay for certain procedures, services or items.
- o Independent professionals, e.g. doctor, physical therapist, may not leave clear instructions for resident and staff to follow.
- o The resident or family may be contributing to the problem.

Consider possible solutions, keeping the outcome the resident wants as your focus

- o What might resolve the problem?
- o What will it take to keep it from recurring?
- o How many possible solutions can be identified?

Identify potential obstacles to resolution

- o What are potential barriers to achieving the outcome the resident wants?
- o How might each barrier be avoided or overcome?

Stage 3: Resolution and Follow-Up

Choose an approach

- What strategies might be effective in getting the outcome the resident wants?
- Who will need to be involved in determining and agreeing to the outcome?
- What information needs to be provided?
- Seek feedback and assistance from the resident before proceeding with resolution.
- Discuss your thoughts about approaching resolution with the resident.
- Make adjustments based upon what the resident says.

Pursue resolution: act to resolve the problem

- Move forward with the plan you and the resident have developed.
- Be flexible with alternatives as long as they are acceptable to the resident.
- Obtain a resolution that is clear regarding what will happen, when, and who will be involved.
- Be sure the resident understands and agrees with the resolution.
- Know who to contact if the resolution is not adequately implemented.

Evaluate the outcome

- Check back with the resident to evaluate the outcome.
- Is the problem solved? Is it partially solved?
- If not, look for new approaches or information, etc., and start again.
- If the problem cannot be resolved within the facility, consider other avenues for resolution.

PROGRAM GUIDANCE: WORKING WITH RESIDENTS WITH OPPOSING VIEWS

Developed for the West Virginia LTCOP by Sara S. Hunt, Consultant

BACKGROUND

Ombudsman Responsibilities

Long term care ombudsmen (LTCO) are mandated to resolve complaints on behalf of residents and to represent the interests of residents before governmental officials. Federal and state laws are clear that the ombudsman's responsibility is to *residents*. Dilemmas sometimes arise in situations where the needs and rights of one resident seem to infringe upon those of other residents. This paper offers guidance for ombudsmen in working through some of these situations.

<u>WV LTCOP Policy Manual Outline</u>

A. Where representing one resident puts other residents in jeopardy or where representing one resident whose interests are adverse to another resident(s).

1. When it appears that the ombudsman is being asked to represent one resident whose interests are potentially adverse to those of other residents, the ombudsman shall engage in preliminary fact-finding before deciding to investigate the complaint. The ombudsman may review resident assessment, care plan and any intervention on the part of the facility before reaching a decision. The ombudsman shall document such facts in the record and shall notify the State Long Term Care Ombudsman, as required by the Code, if he or she decides not to investigate the case.

Code of Ethics for LTCO[7]

This code contains the following provisions directly relevant to resident issues.

1. The Ombudsman provides services with respect for human dignity and the individuality of the client unrestricted by considerations of age, social or economic status, personal characteristics or lifestyle choices.

2. The Ombudsman respects and promotes the client's right to self-determination.

3. The Ombudsman makes every reasonable effort to ascertain and act in accordance with the client's wishes.

4. The Ombudsman acts to protect vulnerable individuals from abuse and neglect.

[7]Developed and adopted by the National Association of State Long Term Care Ombudsman Programs.

Facility Responsibility

Certified nursing facilities are required to meet the needs of *each* resident. While there are many provisions of the law and regulations that list specific areas that must be addressed for *each* resident, there are two primary provisions that encompass all of the detailed ones. They are known as quality of life and quality of care.

Quality of Life

A nursing facility must care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.[8]

Quality of Care

A nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care which...[9]

8USC Vol. 42, '1395i-3(b)(1)(A), '1396r(b)(1)(A).
9USC Vol. 42, '1395i-3(b)(2), '1396r(b)(2).

OMBUDSMAN ROLE IN ISSUES OF RESIDENTS WITH OPPOSING VIEWS

The focus of this paper is dilemmas between, or among, residents with opposing needs or desires. Situations which can be dealt with by engaging both residents in a problem-solving discussion are not included because they are typically more straightforward to resolve.

Working on Behalf of All Residents

Obviously LTCO represent the resident's perspective. To maintain credibility in the ombudsman role, LTCO must avoid taking sides or being viewed as playing favorites. The LTCO goal is to work things out for the benefit of all residents to the greatest extent possible.

Safety Issues

In working to achieve what residents want, LTCO must remember that facilities have to comply with the Life Safety Code and other safety requirements for the benefit of everyone. Ombudsmen also know that residents, like everyone else, have the right to take informed risks and to make decisions others might view as unsafe. Dilemmas arise when one resident's actions threaten the health and safety of other residents.

Legal Issues

Ombudsmen do not represent residents in seeking to pursue illegal activities.

GUIDANCE

Core Principles

The following LTCOP principles are understood as always applicable and will not be repeated for each situation discussed throughout this paper.

- Empower others: LTCO initially provides information and encourages resident or complainant to act on their own behalf with minimal LTCO involvement
- Confidentiality: LTCO does not reveal the identity of resident without permission
- Begin with the resident: LTCO works on behalf of the resident. When a complaint is referred by someone else, the LTCO determines, to the extent possible, what the resident wants before intervening.

Avoid

Long Term Care Ombudsmen need to avoid the following in deciding how to proceed in cases where there are opposing views between residents.

- Taking a position that is, or may be perceived as, saying one resident=s rights are more important than those of another resident.
- Letting the LTCO's values and biases influence the resident=s ability to access LTCOP services.
- Deciding that what one resident wants is out of bounds@ without pursuing possibilities.
- Having a LTCO represent each resident in a dispute, i.e. two ombudsmen and two residents. The LTCOP works on behalf of all residents seeking solutions which satisfy both, or all, residents.

Application

If there is an immediate, life threatening crisis, the facility needs to respond to protect all residents. This guidance applies to other types of situations where a resident wants ombudsman assistance.

Typical LTCO Process in Cases Where Residents Have Opposing Views
The following steps apply to all cases. They are not repeated in the specific situations that follow. This outline represents typical questions LTCO might ask, or try to determine, in order to fully understand the dynamics underlying the opposing perspectives.

- LTCO thoroughly investigates the entire situation to gain facts including the perspective of residents involved in the dispute (or residents whom someone alleges are suffering or will potentially be harmed by another resident) as well as the facility staff's perspective. As appropriate, include an examination of:
    - The perspective of each resident. What does each resident really want? Is the stated issue, the real one or does the resident really want or need something else and the behavior or demand is a signal for attention to an unmet need? Get to the bottom line: what is most important about this situation to each resident? Can outside resources be utilized to help facility staff identify and meet the needs of the residents?
    - What has the facility done to understand and accommodate the needs of all affected residents? Has more than one attempt at resolution occurred? Does the facility understand the underlying dynamics?

- How has facility staff communicated with residents who are affected by one resident's needs or desires?[1]

- Been respectful of resident's confidentiality?
- Listened to and understood the concerns of other residents?
- Explained what the facility is doing to accommodate everyone?
- Asked other residents for ideas regarding resolution?

o Work to resolve the issue in a way that upholds, to the greatest extent possible, individual choice and preference as well as other rights for all residents.

- This might entail some short term, interim solutions, until other factors can be analyzed or put in place.

- Promote a dialogue with all affected residents regarding residents needs and rights and facility responsibility.

- Consider the perception of the LTCOP that may occur as a result of the resolution of this issue. If necessary, take steps to assure other residents, family, or staff, that the LTCOP serves all residents, no one individual=s rights are more important than those of another person. Education about rights, good care practices, or facility responsibility, might be necessary. This might also be a preventive step to avoid future conflicts and misunderstandings.

- Consult with the Regional Ombudsman Supervisor, the State LTC Ombudsman, and/or the Ombudsman Support Attorney, as appropriate in working through these issues.

o In ALL cases, clearly document your ombudsman activities.

[1]Any issues discussed at a resident council meeting or with other residents need to protect the confidentiality of affected residents. LTCO avoid specific reference(s) to a resident at the council meeting but encourage staff to meet with concerned residents away from the meeting in a one-on-one setting.

Situational Dilemmas

Situation	Considerations for ombudsman
Competent resident insists on violating facility policies or state or federal regulations regarding safety or payment of facility bills	• Has the policy/regulation been explained to resident in a way that the resident understands? • Has the facility tried to understand the resident's desire? Has more than one staff person talked with and/or observed the resident? Example: Is it really an issue of smoking in his own room or is it an issue of having no control over basic, daily patterns and routines? Is it a need to have some recognition and respect as an *individual*? • Has the facility tried several alternate ways to accommodate the resident's desire while protecting other residents? • Has the ombudsman determined that the resident is deliberately breaking the policies and/or regulations? • Does the resident understand the consequences of continuing to violate these policies and/or regulations, e.g. involuntary discharge? • Are there other approaches or resources that the ombudsman can identify to bring into this situation? ➢ At some point, the ombudsman might need to tell the resident that no further ombudsman action can be taken. In the future, if the resident has a different issue, or changes his mind, the ombudsman will be responsive.

One resident's practices are offensive or intimidating to other residents. These practices do not violate policies, regulations, or laws. Such practices might include music, videos, language, visiting with friends in the facility.	• What has the facility done to address this issue? • Why is the resident engaging in this behavior? Past patterns? For enjoyment? For control over basic, daily patterns and routines? A need to have some recognition as an *individual*? Sees nothing wrong, offensive, or intimidating in it? Expressing anger with her life situation? • Determine specifics regarding what other residents find intimidating or offensive about this resident's practices. Is it a cultural difference? Is it a values difference? Is it a stereotype? Is it the noise level? Time of day? Size of the group? Is it fear for personal safety? • Does the resident understand how her practices affect other residents? • Seek to resolve: Inform resident that ombudsmen serve *all* residents;

Situation	Considerations for ombudsman
	• Discuss creative solutions. • Bridge the gap in understanding by promoting a dialogue between, or activities with, this resident and others if appropriate. OR support the social worker or activities professional in doing this. ➢ if another facility could better accommodate this resident, inform the resident that options are available. ➢ try to find solutions that meet the needs of all residents to the greatest degree possible. • Systems advocacy: ➢ If this type of situation occurs several times, analyze to determine if a regional or statewide intervention is needed. ➢ If so, consider establishing a coalition to develop and implement strategies to address the issue. ➢ Inform and involve the State LTCO in this.
Interaction between residents is viewed as inappropriate by staff, other residents, or family members.	• How do the involved residents view the situation? • Determine *who* has a problem. • Why the interaction is deemed inappropriate? • Cultural difference? • Values difference? • Stereotypes? • Noise level? Time of day? Location? • Safety? • Resident consent or decision-making capacity is questioned? • Marital status? • Difference in decision-making capacity? Cognitive ability? • What are the underlying needs of these residents? • How are their needs being met? How might their needs be met? • How does this interaction affect each resident's family relationships?

NOTE: THIS SECTION CONTAINS STATISTICAL INFORMATION AND WILL BE INCLUDED AS AN ADDENDUM

A Profile

of

Older Americans: 2006

Administration on Aging

U.S. Department of Health and Human Services

OUTLINE

HIGHLIGHTS *

- The older population (65+) numbered 36.8 million in 2005, an increase of 3.2 million or 9.4% since 1995.

- The number of Americans aged 45-64 – who will reach 65 over the next two decades – increased by 40% during this decade.

- About one in every eight, or 12.4 percent, of the population is an older American.

- Persons reaching age 65 have an average life expectancy of an additional 18.4 years (19.8 years for females and 16.8 years for males).

- Older women outnumber older men at 21.4 million older women to 15.4 million older men.

- In 2005, 18.5% of persons 65+ were minorities--8.3% were African-Americans.** Persons of Hispanic origin (who may be of any race) represented 6.2% of the older population. About 3.1% of the elderly were Asian or Pacific Islander,** and less than 1% were American Indian or Native Alaskan.** In addition, 0.6% of persons 65+ identified themselves as being of two or more races.**

- Older men were much more likely to be married than older women--72% of men vs. 42% of women (Figure 2). 43% older women in 2005 were widows.

- About 30 percent (10.6 million) of non-institutionalized older persons live alone (7.7 million women, 2.9 million men).

- Half of older women age 75+ live alone.

- About 445,000 grandparents aged 65 or more had the primary responsibility for their grandchildren who lived with them.

- The population 65 and over will increase from 35 million in 2000 to 40 million in 2010 (a 15% increase) and then to 55 million in 2020 (a 36% increase for that decade).

- The 85+ population is projected to increase from 4.2 million in 2000 to 6.1 million in 2010 (a 40% increase) and then to 7.3 million in 2020 (a 44% increase for that decade).

- Members of minority groups are projected to increase from 5.7 million in 2000 (16.4% of the elderly population) to 8.1 million in 2010 (20.1% of the elderly) and then to 12.9 million in 2020 (23.6% of the elderly).

- The median income of older persons in 2005 was $21,784 for males and $12,495 for females. Median money income of all households headed by older people (after adjusting for inflation) rose by 2.8% from 2004 to 2005. Family households headed by older people reported a median income in 2005 of $37,765.

- Major sources of income for older people were: Social Security (reported by 89 percent of older persons), income from assets (reported by 55 percent), private pensions (reported by 29 percent), government employee pensions (reported by 14 percent), and earnings (reported by 24 percent).

- Social Security constituted 90% or more of the income received by 34% of all Social Security beneficiaries (21% of married couples and 43% of non-married beneficiaries).

- About 3.6 million elderly persons (10.1%) were below the poverty level in 2005 which was not statistically significant from the poverty rate in 2004.

- About 11% (3.7 million) of older Medicare enrollees received personal care from a paid or unpaid source in 1999.

*Principal sources of data for the Profile are the U.S. Bureau of the Census, the National Center on Health Statistics, and the Bureau of Labor Statistics. The Profile incorporates the latest data available but not all items are updated on an annual basis.

THE OLDER POPULATION

The older population--persons 65 years or older--numbered 36.8 million in 2005 (the most recent year for which data are available). They represented 12.4% of the U.S. population, about one in every eight Americans. The number of older Americans increased by 3.2 million or 9.4% since 1995, compared to an increase of 13.3% for the under-65 population. However, the number of Americans aged 45-64 – who will reach 65 over the next two decades – increased by 40% during this period.

In 2005, there were 21.4 million older women and 15.4 million older men, or a sex ratio of 139 women for every 100 men. The female to male sex ratio increases with age, ranging from 115 for the 65-69 age group to a high of 218 for persons 85 and over.

Since 1900, the percentage of Americans 65+ has tripled (from 4.1% in 1900 to 12.4% in 2004), and the number has increased almost twelve times (from 3.1 million to 36.3 million). The older population itself is getting older. In 2005, the 65-74 age group (18.6 million) was over 8.5 times larger than in 1900, but the 75-84 group (13.1 million) was 17 times larger and the 85+ group (5.1 million) was 42 times larger.

In 2003, persons reaching age 65 had an average life expectancy of an additional 18.4 years (19.8 years for females and 16.8 years for males).

A child born in 2004 could expect to live 77.9 years, about 30 years longer than a child born in 1900. Much of this increase occurred because of reduced death rates for children and young adults. However, the period of 1983-2003 also has seen reduced death rates for the population aged 65-84, especially for men – by 29.4% for men aged 65-74 and by 22.3% for men aged 75-84. Life expectancy at age 65 increased by only 2.5 years between 1900 and 1960, but has increased by 4.3 years from 1960 to 2004.

Over 2.0 million persons celebrated their 65th birthday in 2005. In the same year, about 1.8 million persons 65 or older died. Census estimates showed an annual net increase of almost 500,000 in the number of persons 65 and over. There were 70,104 persons aged 100 or more in 2005 (0.19% of the total population). This is an 88% increase from the 1990 figure of 37,306.

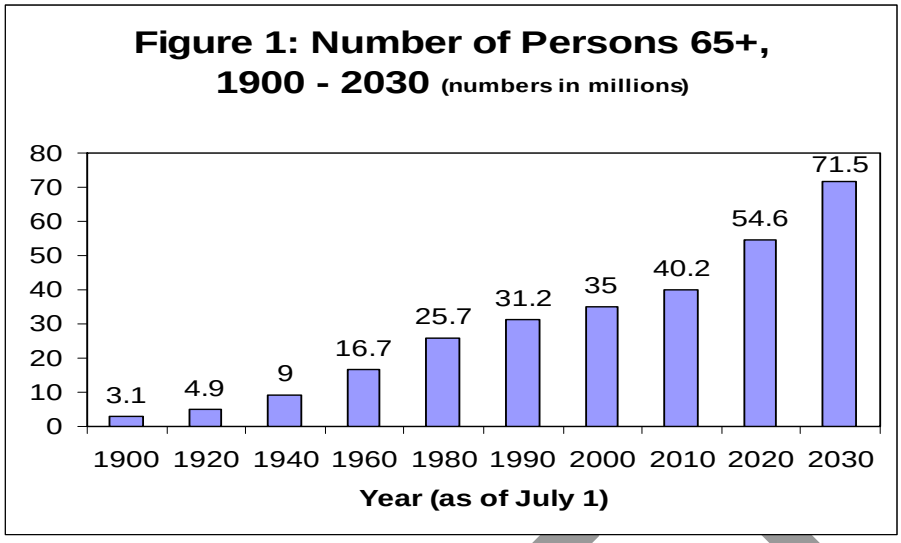
(Data for this section were compiled primarily from Internet releases of the U.S. Bureau of the Census and the National Center for Health Statistics).

FUTURE GROWTH

The older population will continue to grow significantly in the future see Figure 1). This growth slowed somewhat during the 1990's because of the relatively small number of babies born during the Great Depression of the 1930's. But the older population will burgeon between the years 2010 and 2030 when the "baby boom" generation reaches age 65.

The population 65 and over will increase from 35 million in 2000 to 40 million in 2010 (a 15% increase) and then to 55 million in 2020 (a 36% increase for that decade). By 2030, there will be about 71.5 million older persons, almost twice their number in 2005. People 65+ represented 12.4% of the population in the year 2005 but are expected to grow to be 20% of the population by 2030. The 85+ population is projected to increase from 4.2 million in 2000 to 6.1 million in 2010 (40%) and then to 7.3 million in 2020 (44% for that decade).

Minority populations are projected to increase from 5.7 million in 2000 (16.4% of the elderly population) to 8.1 million in 2010 (20.1% of the elderly) and then to 12.9 million in 2020 (23.6% of the elderly). Between 2004 and 2030, the white** population 65+ is projected to increase by 74% compared with 183% for older minorities, including Hispanics (254%), African-Americans** (147%), American Indians, Eskimos, and Aleuts** (143%), and Asians and Pacific Islanders** (208%).

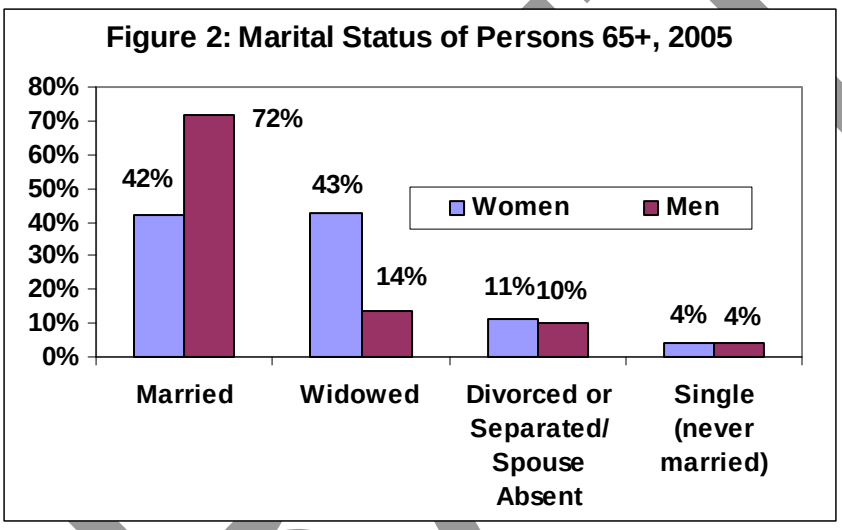


Note: Increments in years are uneven.
(Sources: Projections of the Population by Age are taken from the January 2004 Census Internet Release. Historical data are taken from "65+ in the United States," Current Population Reports, Special Studies, P23-190 Data for 2000 are from the 2000 Census and 2005 data are taken from the Census estimates for 2005.)

MARITAL STATUS

In 2005, older men were much more likely to be married than older women--72% of men, 42% of women (Figure 2). Almost half of all older women in 2005 were widows (43%). There were over four times as many widows (8.6 million) as widowers (2.1 million).

Divorced and separated (including married/spouse absent) older persons represented only 10.8% of all older persons in 2005. However, this percentage has increased since 1980, when approximately 5.3% of the older population were divorced or separated/spouse absent.



(Based on Internet releases of data from the 2005 Current Population Survey, Annual Social and Economic Supplement of the U.S. Bureau of the Census)

LIVING ARRANGEMENTS

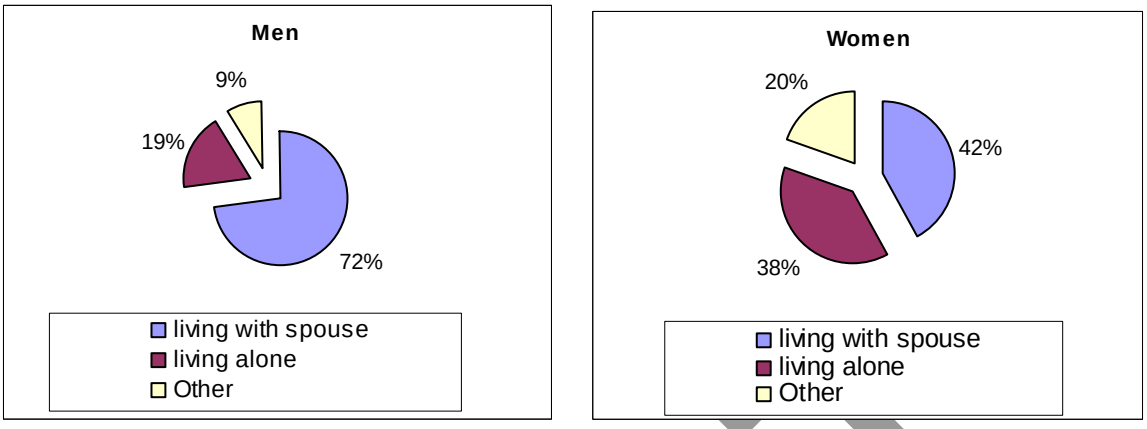
Over half (54.8%) the older non-institutionalized persons lived with their spouse in 2005. Approximately 10.9 million or 71.7% of older men, and 8.4 million or 42.0% of older women, lived with their spouse (Figure 3). The proportion living with their spouse decreased with age, especially for women. Only 30.2% of women 75+ years old lived with a spouse.

About 30.1% (10.6 million) of all non-institutionalized older persons in 2005 lived alone (7.7 million women, 2.9 million men). They represented 38.4 of older women and 19.2% of older men. The proportion living alone increases with advanced age. Among women aged 75 and over, for example, half (47.7%) lived alone.

More than 685,000 grandparents aged 65 or over maintained households in which grandchildren were present in 2005. (Another 218,000 elderly were spouses of such people.) In addition, 660,000 grandparents over 65 years lived in parent- maintained households in which their grandchildren were present. A total of about 1.57 million older people lived in household with a grandchild present in the house. About 445,000 of these grandparents over 65 years old were the persons with primary responsibility for their grandchildren who lived with them.

While a relatively small number (1.56 million) and percentage (4.5%) of the 65+ population lived in nursing homes in 2000, the percentage increases dramatically with age, ranging from 1.1% for persons 65-74 years to 4.7% for persons 75-84 years and 18.2% for persons 85+. In addition, approximately 5% of the elderly lived in self-described senior housing of various types, many of which have supportive services available to their residents.

Figure 3: Living Arrangements of Persons 65+, 2005



(Based on data from U.S. Bureau of the Census including the 2005 Current Population Survey, Annual Social and Economic Supplement and the 2005 American Community Survey. See: March 2005 Current Population Survey Internet releases, Detailed Tables. and "The 65 Years and Over Population: 2000, Census 2000 Brief, October, 2001" as well as other Census 2000 data and unpublished data from the Centers for Medicare and Medicaid Services.)

RACIAL AND ETHNIC COMPOSITION

In 2005, 18.5% of persons 65+ were minorities--8.3% were African-Americans.** Persons of Hispanic origin (who may be of any race) represented 6.2% of the older population. About 3.1 were Asian or Pacific Islander,** and less than 1% were American Indian or Native Alaskan.** In addition, 0.6% of persons 65+ identified themselves as being of two or more races.

Only 7.0% of minority race and Hispanic populations were 65+ in 2005 (8.4% of African-Americans,** 8.8% of Asians and Pacific Islanders,** 7.5% of American Indians and Native Alaskans,** 5.4% of Hispanics), compared with 15.1% of non-Hispanic whites.**

(Data for this section were compiled from Internet releases of the Census 2005 Population Estimates).

GEOGRAPHIC DISTRIBUTION

The proportion of older persons in the population varies considerably by state with some states experiencing much greater growth in their older populations (Figures 4 and 5). In 2005, about half (51.6%) of persons 65+ lived in nine states. California had 3.9 million; Florida 3.0 million; New York 2.5 million; Texas 2.3 million; and Pennsylvania 1.9 million, Illinois, Ohio, Michigan, and New Jersey each had well over 1 million (Figure 6).

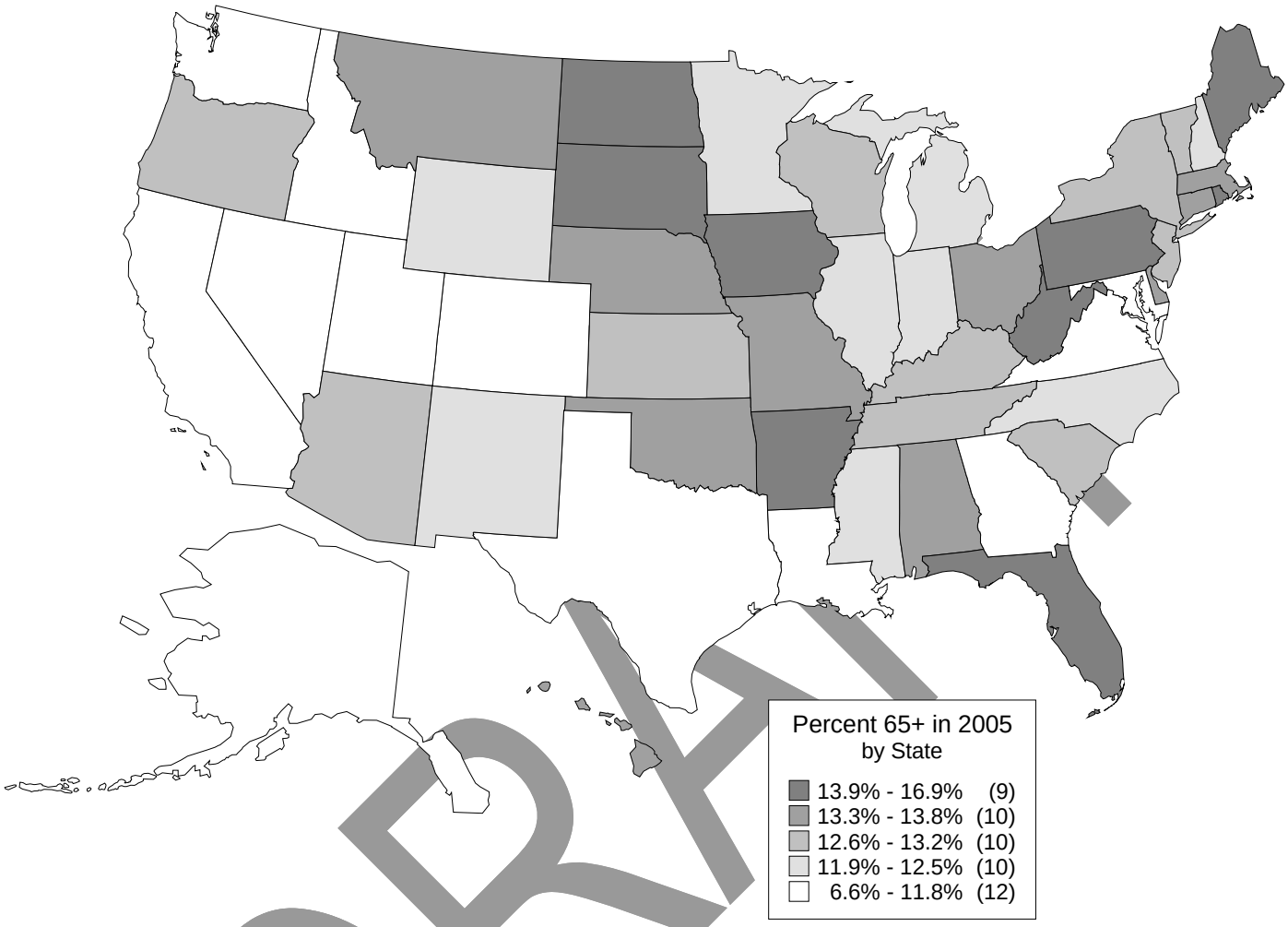
Person 65+ constituted approximately 14% or more of the total population in 8 states in 2005 (Figure 6): Florida (16.8%); West Virginia (15.3%); Pennsylvania (15.2%); North Dakota (14.7%); Iowa (14.7%); Maine (14.6); South Dakota (14.2); and Rhode Island (13.9%). In ten states, the 65+ population increased by 20% or more between 1995 and 2005 (Figure 6): Nevada (56.6%); Alaska (47.5%); Arizona (31.4%); New Mexico (26.5%); Utah (24.1%); Colorado (23.3%); Delaware (22.9%); Idaho (22.8%); Georgia (20.8%) and South Carolina (20.6%). The ten jurisdictions with the highest poverty rates for elderly during 2005 were the District of Columbia (17.6%); Mississippi (15.7%); Louisiana (15.6%); Arkansas (14.5%); North Dakota (14.1%); Kentucky (13.5%); Tennessee (13.1%); Alabama (13.1%); Georgia (13.0%); and New York (12.8%).

Most persons 65+ lived in metropolitan areas in 2005 (79.8%). About 50% of older persons lived in the suburbs, 29% lived in central cities, and 20% lived in nonmetropolitan areas.

The elderly are less likely to change residence than other age groups. From 2004 to 2005 only 4.2% of older persons moved as opposed to 13.4% of the under 65 population. Most older movers (51.6%) stayed in the same county and 72.1% remained in the same state. Only 25.5% (of the movers) moved out-of-state.

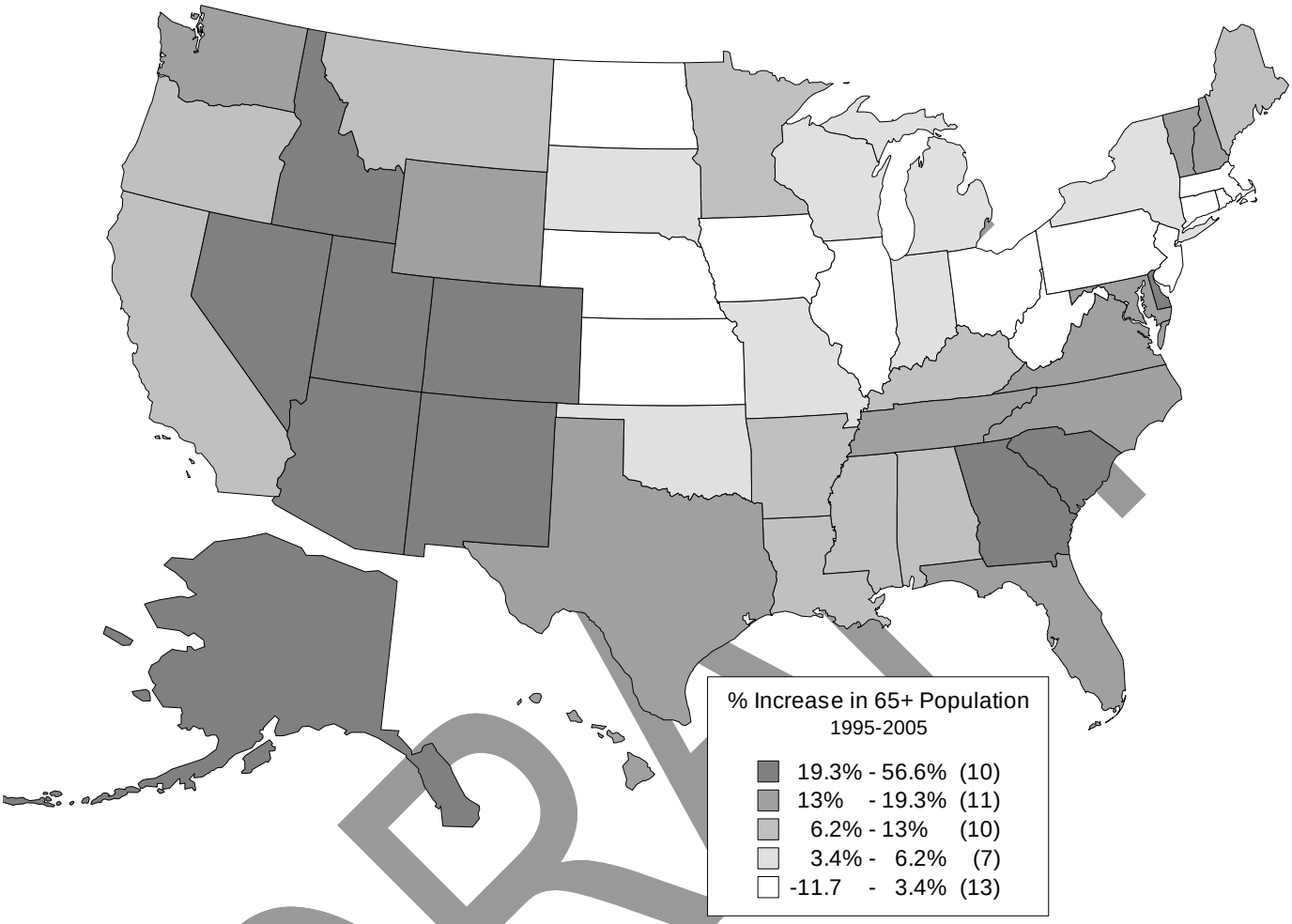
(Data for this section and for Figure 4 were compiled primarily from the Census Population Estimates for 2005 as well as other Internet releases of the U.S. Bureau of the Census including tables from the March 2005 Current Population Survey, Annual Social and Economic Supplement)

Figure 4: Persons 65+ as a Percentage of Total Population, 2005



(Source: 2005 Population Estimates from the U.S. Bureau of the Census)

Figure 5: Percentage Increase in Population 65+, 1995 to 2005



(Source: 1995 and 2005 Population Estimates from the U.S. Bureau of the Census)

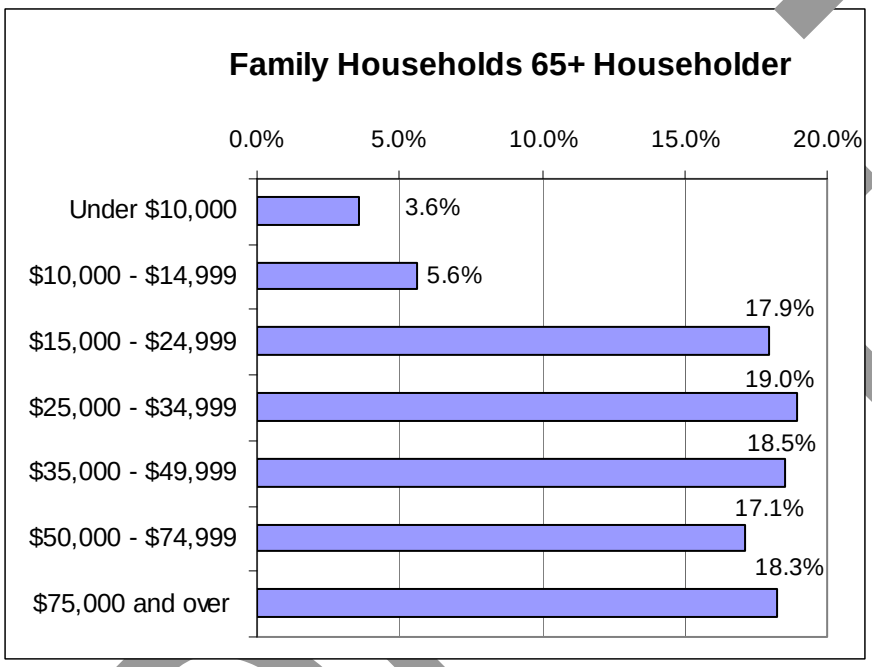
Figure 6: The 65+ Population by State: 2005				
Numbers	Number of Persons	Percent of All Ages	Percent Increase from 1995 to 2005	Percent Below Poverty 2005
US Total (50 States + DC)	36,790,113	12.4%	9.4%	10.1%
Alabama	603,733	13.2%	8.4%	13.1%
Alaska	44,026	6.6%	47.5%	9.1%
Arizona	758,181	12.8%	31.4%	8.1%
Arkansas	384,450	13.8%	6.2%	14.5%
California	3,868,574	10.7%	11.9%	8.2%
Colorado	465,096	10.0%	23.3%	8.6%
Connecticut	474,150	13.5%	1.5%	7.5%
Delaware	112,214	13.3%	22.9%	7.5%
District of Columbia	67,208	12.2%	-11.6%	17.6%
Florida	2,993,160	16.8%	13.9%	10.3%
Georgia	870,422	9.6%	20.8%	13.0%
Hawaii	174,538	13.7%	16.8%	9.3%
Idaho	163,917	11.5%	22.8%	8.7%
Illinois	1,530,074	12.0%	2.2%	8.7%
Indiana	777,506	12.4%	5.7%	8.0%
Iowa	435,220	14.7%	0.2%	8.0%
Kansas	357,005	13.0%	0.5%	7.9%
Kentucky	525,764	12.6%	7.7%	13.5%
Louisiana	531,581	11.8%	7.4%	15.6%
Maine	192,664	14.6%	11.5%	11.0%
Maryland	644,560	11.5%	13.0%	7.9%
Massachusetts	852,826	13.3%	-0.6%	10.0%
Michigan	1,258,494	12.4%	4.6%	8.6%
Minnesota	623,241	12.1%	8.3%	8.4%
Mississippi	358,393	12.3%	7.6%	15.7%
Missouri	773,171	13.3%	4.0%	9.1%
Montana	128,834	13.8%	12.3%	9.1%
Nebraska	233,550	13.3%	1.9%	8.7%
Nevada	273,136	11.3%	56.6%	8.3%
New Hampshire	163,105	12.5%	18.4%	6.9%
New Jersey	1,129,356	13.0%	3.4%	8.7%
New Mexico	234,902	12.2%	26.5%	12.5%
New York	2,515,064	13.1%	4.0%	12.8%
North Carolina	1,054,098	12.1%	16.4%	12.1%
North Dakota	93,650	14.7%	0.0%	14.1%
Ohio	1,529,430	13.3%	2.2%	8.4%
Oklahoma	468,968	13.2%	5.6%	11.2%
Oregon	469,906	12.9%	10.2%	7.9%
Pennsylvania	1,892,847	15.2%	-1.0%	9.0%
Rhode Island	149,775	13.9%	-3.7%	7.8%
South Carolina	534,980	12.6%	20.6%	11.5%
South Dakota	110,530	14.2%	4.7%	12.5%
Tennessee	749,951	12.6%	13.3%	13.1%
Texas	2,271,845	9.9%	19.3%	12.7%
Utah	216,021	8.7%	24.1%	6.5%
Vermont	81,982	13.2%	15.9%	10.0%
Virginia	865,103	11.4%	17.4%	9.8%
Washington	720,874	11.5%	14.1%	8.7%
West Virginia	278,368	15.3%	0.2%	11.6%
Wisconsin	721,633	13.0%	5.3%	7.7%
Wyoming	62,037	12.2%	16.8%	8.0%
Puerto Rico	489,819	12.5%		44.3%

- ***(Source: Population data is from Census Bureau Population Estimates. Poverty data is from the 2005 American Community Survey.)***

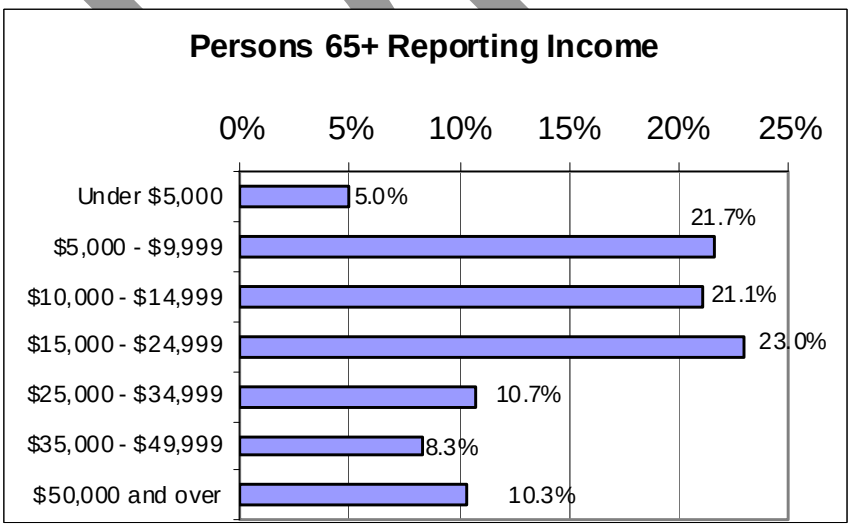
INCOME

The median income of older persons in 2005 was $21,784 for males and $12,495 for females. Median money income of all households headed by older people rose by 2.8% from 2004 to 2005. Households containing families headed by persons 65+ reported a median income in 2005 of $37,765 ($39,402 for non-Hispanic Whites, $27,270 for African-Americans, $49,163 for Asians, and $26,681 for Hispanics). About one of every ten (9.2%) family households with an elderly householder had incomes less than $15,000 and 53.9% had incomes of $35,000 or more (Figure 7).

Figure 7: Percent Distribution by Income: 2005*



$37,765 median for 12.2 million family households 65+



$15,696 median for 34.4 million persons 65+ reporting income

For all older persons reporting income in 2005 (34.4 million), 26.7% reported less than $10,000. Only 29.3% reported $25,000 or more. The median income reported was $15,696.

The major sources of income as reported by older persons in 2004 were Social Security (reported by 89% of older persons), income from assets (reported by 55%), private pensions (reported by 29%), government employee pensions (reported by 14%), and earnings (reported by 24%). In 2004, Social Security benefits accounted for 39% of the aggregate income of the older population. The bulk of the remainder consisted of earnings (26%), asset income (13%), and pensions (19%). Social Security constituted 90% or more of the income received by 34% of beneficiaries (21% of married couples and 43% of non-married beneficiaries).

(Based on data from Current Population Survey, Annual Social and Economic Supplement, "Income, Poverty, and Health Insurance Coverage in the United States: 2005" P60-231, issued August, 2006 by the U.S. Bureau of the Census, related Census detailed tables on the Census Bureau web site, and from Fast Facts and Figures About Social Security, 2005 Social Security Administration)

POVERTY

About 3.6 million elderly persons (10.1%) were below the poverty level in 2005. This poverty rate was not statistically significant from the poverty rate in 2004. The historic lowest level of 9.7% was reached in 1999. Another 2.3 million or 6.6% of the elderly were classified as "near-poor" (income between the poverty level and 125% of this level).

One of every twelve (7.9%) elderly Whites** was poor in 2005, compared to 23.2% of elderly African-Americans, 12.6% of Asians, and 19.9% of elderly Hispanics. Higher than average poverty rates were found in 2004 for older persons were found among those who lived in principal cities (12.7%), outside metropolitan areas (i.e. rural areas) (11.9%), and in the South (12.0%).

Older women had a higher poverty rate (12.3%) than older men (7.3%) in 2005. Older persons living alone were much more likely to be poor (19.1%) than were older persons living with families (5.6%). The highest poverty rates were experienced among Hispanic women (45.9%) and also by older Black women (36.7%) who lived alone.
(Based on data from Current Population Survey, Annual Social and Economic Supplement, "Income, Poverty, and Health Insurance Coverage in the United States: 2005," P60-231, issued August, 2006, by the U.S. Bureau of the Census and related Census detailed tables on the Census Bureau web site)

HOUSING

Of the 2.2 million households headed by older persons in 2005, 80% were owners and 20% were renters. The median family income of older homeowners was $26,899. The median family income of older renters was $13,377. In 2005, 48% of older householders spent more than one-fourth of their income on housing costs - 43% for owners and 82% for renters - as compared to 37% of all householders.

For homes of older householders in 2005, the median construction year was 1966 (it was 1974 for all householders) and 4.7% of the homes had physical problems. In 2005, the median value of homes owned by older persons was $143,697 (with a median purchase price of $38,182) compared to a median home value of $165,344 for all homeowners. About 68% of older homeowners in 2005 owned their homes free and clear.

(Source: "Amer. Housing Survey for the United States in 2005, Current Housing Reports" H150/05)

EMPLOYMENT

In 2005, 5.3 million (15.1 %) Americans age 65 and over were in the labor force (working or actively seeking work), including 3.0 million men (19.8%) and 2.3 million women (11.5%). They constituted 3.5% of the U.S. labor force. About 3.5% were unemployed. Labor force participation of men 65+ decreased steadily from 2 of 3 in 1900 to 15.8% in 1985, and has stayed at 16%-18% since then. The participation rate for women 65+ rose slightly from 1 of 12 in 1900 to 10.8% in 1956, fell to 7.3% in 1985, and has been around 8%-10% since 1988.

(Source: Current Population Survey, labor force statistics. See: Bureau of Labor Statistics web-site: http://www.bls.gov/cps/home.htm)

EDUCATION

The educational level of the older population is increasing. Between 1970 and 2005, the percentage who had completed high school rose from 28% to 74%. Almost 19% in 2005 had a bachelor's degree or more. The percentage who had completed high school varied considerably by race and ethnic origin in 2005: 79% of Whites**, 66% of Asians and Pacific Islanders, 54% of African-Americans, and 40% of Hispanics. The increase in educational levels is also evident within these groups. In 1970, only 30% of older Whites and 9% of older African-Americans were high school graduates.

(Source: Current Population Survey, Annual Social and Economic Supplement, 2005 and related tables on the Census Bureau web site)

HEALTH AND HEALTH CARE

In 2005, 38.3% of non-institutionalized older persons assessed their heath as excellent or very good (compared to 66.8% for persons aged 18-64). There was little difference between the sexes on this measure, but African-Americans** (22.8%), older American Indians/Alaska Natives (24.2%) and older Hispanics (28.4%) were less likely to rate their health as excellent or good than were older Whites** (40.9%) or older Asians (34.9%).† Most older persons have at least one chronic condition and many have multiple conditions. Among the most frequently occurring conditions older persons in 2004-2005 were: hypertension (48%), diagnosed arthritis (47%), all types of heart disease (29%), any cancer (20%), diabetes (16%), and sinusitis (14%).

Almost 60% reported in 2005 that they received an influenza vaccination during the past 12 months and 56% reported that they had ever received a pneumococcal vaccination. About 24% (of persons 60+) report height/weight combinations that place them among the obese. Over 25% of persons aged 65-74 and 17% of persons 75+ report that they engage in regular leisure-time physical activity. Only 9% reported that they are current smokers and only 4% reported excessive alcohol consumption. Only 2.6% reported that they had experienced psychological distress during the past 30 days.

In 2004, over 13.2 million persons aged 65 and older were discharged from short stay hospitals. This is a rate of 3,629 for every 10,000 persons aged 65+ which is over two and one half times the comparable rate for persons of all ages (which was 1,384 per 10,000). The average length of stay for persons aged 65+ was 5.6 days; the comparable rate for persons of all ages was 4.8 days. The average length of stay for older people has decreased by 5 days since 1980. Older persons averaged more office visits with doctors

† These figures are from 2004 data.

in 2003-4: 6.1 office visits for those aged 65-74 and 7.6 office visits for persons over 75 while persons aged 45-65 averaged only 3.7 office visits during that year. Over 96% of older persons reported that they did have a usual place to go for medical care and only 2.4% said that they failed to obtain needed medical care during the previous 12 months due to financial barriers.

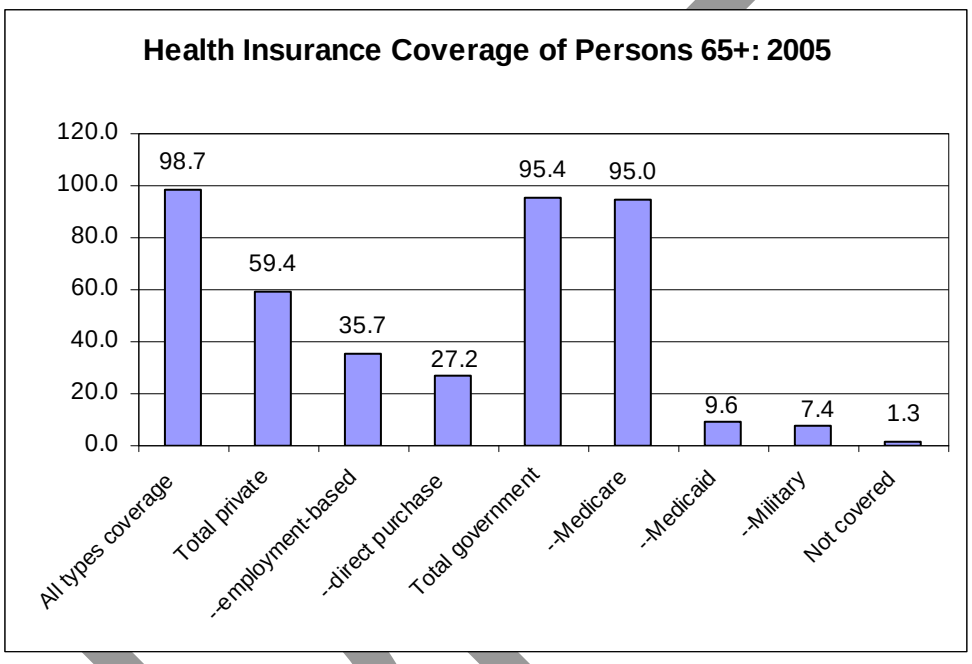
In 2004, older consumers averaged $4193 in out-of-pocket health care expenditures, an increase of 58% since 1994. In contrast, the total population spent considerably less, averaging $2,664 in out-of-pocket costs. Older Americans spent 12.8% of their total expenditures on health, more than twice the proportion spent by all consumers (5.7%). Health costs incurred on average by older consumers in 2004 consisted of $2,307 (55%) for insurance, $977 (23%) for drugs, $769 (18%) for medical services, and $140 (3%) for medical supplies.

*(*Sources: Data releases from the web sites of the National Center for Health Statistics (including the Data Warehouse on Trends in Health and Aging); from the Agency for Healthcare Research and Quality, and from the Bureau of Labor Statistics web site)

HEALTH INSURANCE COVERAGE

In 2005, almost all (95%) non-institutionalized persons 65+ were covered by Medicare. Medicare covers mostly acute care services and requires beneficiaries to pay part of the cost, leaving about half of health spending to be covered by other sources. About 59% had some type of private health insurance. Over 7% had military-based health insurance and 9% of the non-institutionalized elderly were covered by Medicaid. Only 1% did not have coverage of some kind. About 87% of non-institutionalized Medicare beneficiaries in 2004 had some type of supplementary coverage. However, among Medicare beneficiaries residing in nursing homes, almost 58% were covered by Medicaid in 2001.

Figure 8:



Note: Figure 8 data is for the non-institutionalized elderly. A person can be represented in more than one category.

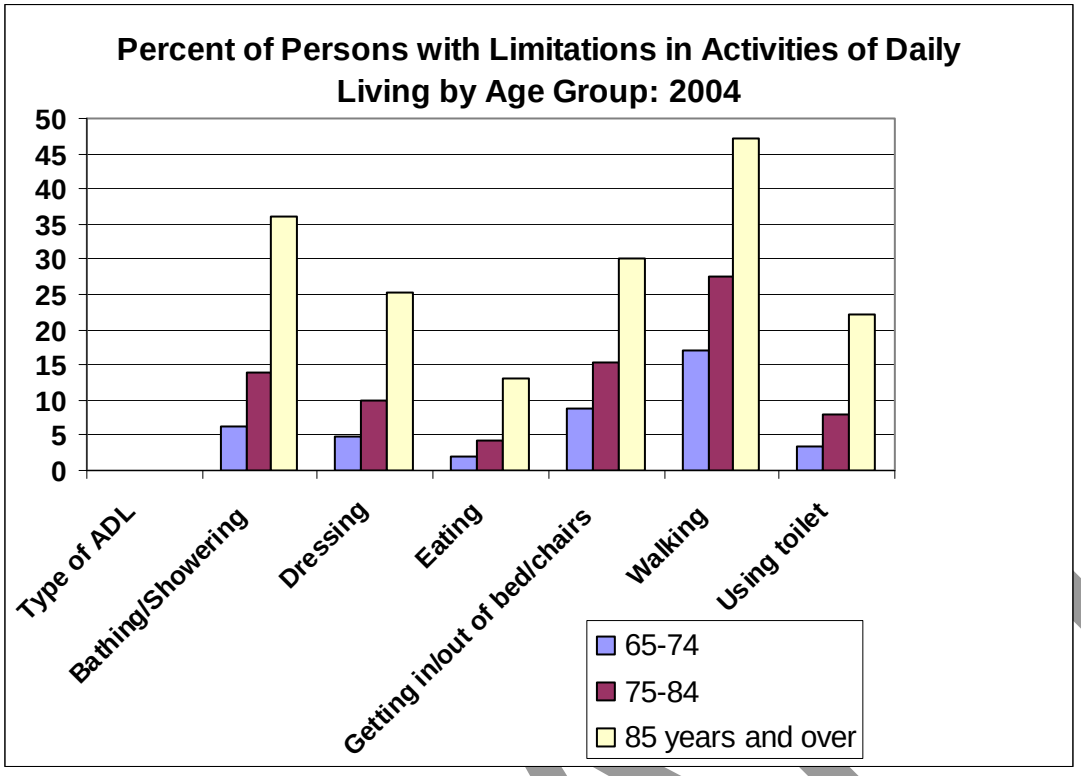
(Source: U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement. Based on Detailed Tables on Health Insurance Coverage, U.S. Bureau of the Census web site. Medicare beneficiary data is from the Medicare Current Beneficiary Survey)

DISABILITY AND ACTIVITY LIMITATIONS

In 2002, 52% of older persons reported that they had some type of disability (sensory disability, physical disability, or mental disability). Some of these disabilities may be relatively minor but others cause people to require assistance to meet important personal needs. Almost 37% of older persons reported a severe disability and 16% reported that they needed some type of assistance as a result. Reported disability increases with age. 57% of persons over 80 reported a severe disability and 30% of the over 80 population reported that they needed assistance. There is a strong relationship between disability status and reported health status. Among those 65+ with a severe disability, 66% reported their health as fair or poor. Among the 65+ persons who reported no disability, only 10.5% reported their health as fair or poor. Presence of a severe disability is also associated with lower income levels and educational attainment.

In another study which focused on the ability to perform specific activities of daily living (ADLs), over 27.1% of community-resident Medicare beneficiaries over age 65 in 2004 had difficulty in performing one or more ADLs and an additional 13.7% reported difficulties with instrumental activities of daily living (IADLs). By contrast, 91.3% of institutionalized Medicare beneficiaries had difficulties with one or more ADLs and 76.5% of them had difficulty with three or more ADLs. [ADLs include bathing, dressing, eating, and getting around the house. IADLs include preparing meals, shopping, managing money, using the telephone, doing housework, and taking medication.] Limitations on activities because of chronic conditions increase with age. As shown in Figure 9 (from another survey), the rate of limitations on activities among persons 85 and older are much higher than those for persons 65-74.

Figure 9:



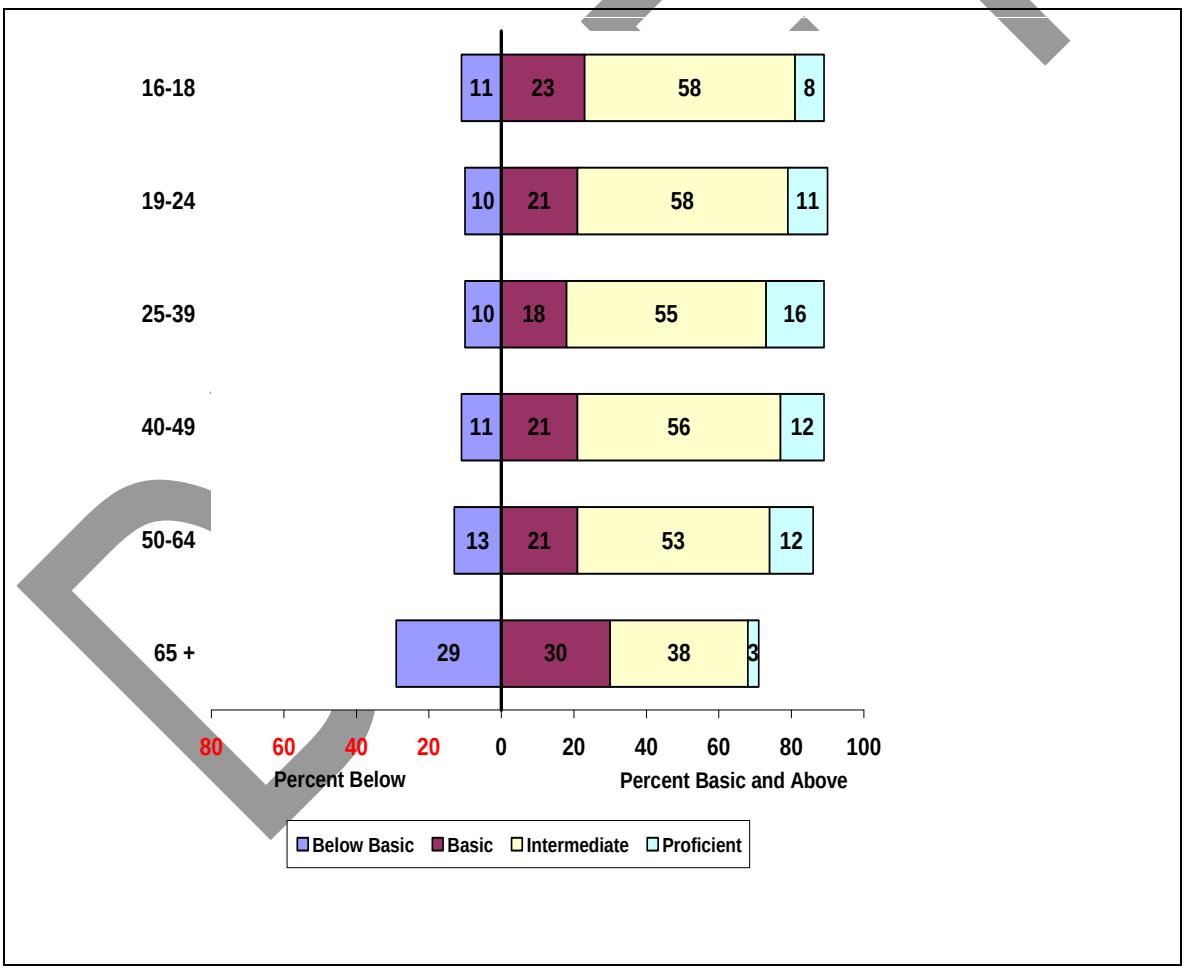
It should be noted that (except where noted) the figures above are taken from surveys of the noninstitutionalized elderly. Although nursing homes are being increasingly used for short-stay post-acute care, about 1.6 million elderly are in nursing homes (about half are age 85 and over). These individuals often have high needs for care with their ADLs and/or have severe cognitive impairment, due to Alzheimer's disease or other dementias.

(Sources: Americans with Disabilities: 2002, May 2006, P70-107 and other Internet releases of the Census Bureau and the National Center on Health Statistics, including the NCHS Data Warehouse on Trends in Health and Aging)

SPECIAL TOPIC: HEALTH LITERACY

Older adult have more chronic conditions, hospital admissions, doctor and ER visits, and expenditures for prescription drugs than younger age groups. Therefore, health literacy, i.e., the ability of individuals to understand basic health information, is critical to the ability of older persons to maintain good health. However, older adults have disproportionately lower health literacy than younger adults. In a recent national survey, the elderly had an average health literacy score within the basic health literacy performance level, while the averages for all other age groups fall into the intermediate performance group. As shown in Figure 10, older adults were also far more likely to have below basic (29%) or basic (30%) health literacy than any other age group.

Figure 10: Percentage of Adult in each Health Literacy Level, by age: 2003



Source: The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006–483). U.S. Department of Education. Washington, DC: National Center for Education Statistics.)

CAREGIVING

About 11% (3.7 million) of older Medicare enrollees received personal care from a paid or unpaid source in 1999. Almost all community resident older persons with chronic disabilities receive either informal care (from family or friends) or formal care (from service provider agencies). Over 90% of these older persons with chronic disabilities received informal care and/or formal care; and about two thirds received only informal care. About 9 % of this chronically disabled group received only formal services.

(Source: National Long Term Care Survey, 1999)

Notes:

*Principal sources of data for the Profile are the U.S. Bureau of the Census, the National Center on Health Statistics, and the Bureau of Labor Statistics. The Profile incorporates the latest data available but not all items are updated on an annual basis.

**Excludes persons of Hispanic origin.

A Profile of Older Americans: 2006 was prepared by the Administration on Aging (AoA), U.S. Department of Health and Human Services. The annual Profile of Older Americans was originally developed and researched by Donald G. Fowles, AoA. Saadia Greenberg, AoA, developed the 2006 edition. Jennifer Klocinski, AoA, contributed the section on health literacy.

AoA serves as an advocate for the elderly within the federal government and is working to encourage and coordinate a responsive system of family and community based services throughout the nation. AoA helps states develop comprehensive service systems which are administer by 56 State and Territorial Units on Aging, 655 Area Agencies on Aging, 226 Native American and Hawaiian organizations, and more than 29,000 local service providers.